PSYCHIATRIC DISABILITY AMONG BHUTANESE REFUGEES LIVING IN NEPAL AND THEIR PERCEPTION OF MENTAL ILLNESS AND DISABILITY

By

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DEDICATION

To all Bhutanese refugees living in Nepal,
To my late grandfather who always inspired me, missed me very much at the last moment of his life and could not wait to witness this piece of work,
To my wife Shailendri and my family

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LIST OF ABBREVIATIONS

AHURA - Associations of Human Rights Activists
CI - 95% Confidence Interval
CIDI - Composite International Diagnostic Interview
CVICT - Centre for Victims of Torture
DALY - Disability Adjusted Life Years
DSM - Diagnostic and Statistical Manual
FGD - Focus Group Discussion
GAD - Generalised Anxiety Disorder
GHQ - General Health Questionnaires
HCL - Hopkins Symptom Checklist
HMG - His Majesty Government
ICD - International Classification of Diseases
ICIDH - International Classification of Impairments, Disabilities, and Handicaps
KAP - Knowledge, Attitude and Practices
OR - Odd's Ratio
PTSD - Post Traumatic Stress Disorder
SD - Standard Deviation
SPSS - Statistical Package for Social Sciences
UNHCR - United Nation's High Commissions for Refugees
WHO - World Health Organisation
WHO DAS-S - World Health Organisation Disability Assessment Schedule- Short

Abstract

Background: Most refugees live in low-income countries. More than one hundred thousand Bhutanese refugees have been living in Nepal for several years. The association of torture and psychiatric morbidity with disability among such refugees is unknown. It is also important to understand how they perceive mental illness and disability.

Objectives: (a) To compare disability between tortured and non-tortured Bhutanese refugees living in Nepal, (b) to investigate psychiatric comorbidity and its association with disability among tortured Bhutanese refugees, (c) to identify predictors of psychiatric disability among Bhutanese refugees living in Nepal, and (d) to assess their knowledge, attitude and practices regarding mental illness and disability

Design and participants: Cross-sectional survey was carried out on a sample of 418 tortured and 392 non-tortured refugees, matched on age and sex. Furthermore, focus group discussions were conducted with 14 mentally ill or disabled refugees, 16 family members and 12 traditional healers in addition to 10 in-depth interviews.

Settings: Bhutanese refugee camps in eastern Nepal.

Main Outcome Measure: Composite International Diagnostic Interview-2.1, and Psychiatric Disability Assessment Schedule-Short (WHO DAS-S) were used to measure psychopatholgy and disability respectively.

Results: Disability among tortured and non-tortured Bhutanese refugees was not significantly different (21% vs 24%, $p = 0.407$). Comorbidity of PTSD with persistent pain, specific phobia and dissociative disorders among tortured refugees were significantly associated with disability. Posttraumatic stress disorder (OR 2.0, 95% CI of 1.2-3.5), specific phobia (OR 2.2, 95% CI of 1.2-3.8), and present physical illness (OR 2.0, 95% CI of 1.1-3.8) were identified as predictors of disability for tortured refugees. On the other hand, generalized anxiety disorder (OR 3.3, 95% CI 1.2-9.3), older age (OR 2.3, 95% CI 1.1-5.1), and present illness (OR 2.9, 95% CI 1.7-5.2) were identified as predictors of disability for non-tortured refugees.

Bhutanese refugees have specific ways of understanding and explaining mental illness and disability. Both mental illness and disability are associated with stigma in this community. Furthermore, most of them believe that mental illness could lead to disturbances in different roles.

Conclusion: Disability was associated with different risk factors for tortured and non-tortured refugees. Comorbidity increased odds for disability. Further studies are needed to generalize findings beyond the Bhutanese refugee population. A combination of quantitative and qualitative research provides a more in-depth picture of the nature and extent of disorders and disability than either research method is able to provide alone.

1.0 INTRODUCTION

1.1 Mental health

The World Health Organisation (WHO) has estimated that today as many as 1500 million people world-wide are suffering at any given time from some kind of neuro-psychiatric disorders, including mental, behavioural and substance abuse disorder. A third may be affected by more than one neuro-psychiatric ailment and three quarters live in developing countries. The impact of mental illness in psychological, social and economic terms is very high. Moreover, at least one out of four people who come to health services for help is troubled by mental disorders, which are often neither correctly diagnosed nor treated (WHO, 2000).

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Even then, the basic epidemiological data on the prevalence and distribution of mental and behaviour health conditions is severely lacking in many low-income countries. Clinical and community epidemiological studies are needed to fill these gaps (Desjaralais et al, 1995). Furthermore, although mental health services have been developed in many countries, research activities have not often been incorporated in their planning (Tantam, 1996). There is a lack of reliable epidemiological data regarding the extent and distribution of mental disorder in the developing world.

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1.2 Refugee and mental health

There are currently 11.5 million refugees in this world, and the majority of them live in poor developing countries (United Nations High Commission for Refugees, 2000). It is estimated that 4.7 million refugees live in Asia alone. Many refugees are at high risk for mental health problems as a direct result of the refugee experience. Primary factors leading to this increased risk are war or trauma experience and displacement. Even a brief contact with war or trauma can have a lasting effect on a person. So far available literature on refugee mental health is by far limited to refugees living in the west (Desjaralais et al, 1995) despite the fact that majority refugee population live in low-income countries. Thus, there is a strong need of a study of mental health among refugees living in the developing countries.

1.3 Disability and mental illness

WHO and ICIDH (International Classification of Impairments, Disabilities and Handicaps) have defined disability as “any restriction or lack resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal depending upon age, sex, and social and cultural factors for that individual”. The WHO estimates that about 40 million people in the world have significant disabilities secondary to chronic mental health problems. Until 1993, when the concepts of Global Burden of Disease emerged, mortality measurement was the only way of determination of the burden of diseases. Since then, public health burden of an illness or disorder has been measured in terms of Disability Adjusted Life Years (DALY). One DALY is one lost year of healthy life. The estimated percentage of DALYs lost by mental health problems is 11.5%. It is also of great significance that 5 of the 10 leading causes of disability worldwide are mental health problems. These are major depression, schizophrenia, bipolar disorders, alcohol abuse, and obsessive compulsive disorders (WHO, 1999). The situation is likely to be worse among

refugees living in the developing countries, and there is so far no study done to examine an association between mental illness and disability among them. Thus, we conducted our study among Bhutanese refugees living in Nepal to see such an association.

Furthermore, both mental illness and disability are highly stigmatised in many societies. The meaning given to both the terms vary a lot from society to society. Thus, mere psychiatric diagnosis and disability measurement do not fully reflect what and how people perceive the disorders back in the society, because many societies still raise barriers to both the care and the reintegration of people with mental illness and associated disability. Taking into account of this fact, WHO decided to celebrate World Health Day, 2001 with the theme "Mental health: stop exclusion-dare to care".

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1.4 Bhutan and its refugees

Bhutan is a small, land-locked, mountainous, poor, developing monarchy nation bounded by Tibet to its North and by India to its east, west, and south. It has an area of 47,000 Sq. Km and total population of 600,000. There are several ethnic groups with their own cultures and languages. In addition to modern allopathic medicine, traditional and spiritual healing and herbal medicine are widely practised in Bhutan. Between 1907 and 1952, Bhutan was in complete isolation from rest of the world. In 1953, the late King initiated some democratic reforms, which were reversed by the current King after he was enthroned in 1974 at an early age of 18 (AHURA Bhutan, 1993).

Almost half of Bhutan's population was of Nepalese origin until 1990. Migration of Nepalese population to Bhutan, as per the request of then Bhutanese rulers, appears to have begun in the 17th century. Most of them have lived in Bhutan for almost a century. They are known as Lhotsampa (southern Bhutanese) as a majority of them inhabited the country's southern districts. They are comparatively better educated and motivated for democracy. The Drukpa minority government, which represents only 15% of total population, felt a threat to their ruling power and, thus gradually wanted to reduce the large number of Bhutanese citizen of Nepalese origin. Among such several attempts, the new citizenship act of 1985 was directed towards this purpose. The southern Bhutanese were banned to practise their Hindu religion and culture and instead were obliged to follow Drukpa culture (AHURA Bhutan, 1993). To protest against this suppression, the southern Bhutanese led a pro-democracy movement in 1989. As a consequence, Bhutanese government intensified its suppression and torture. Because of the persecution by Drukpa government's security forces, more than a hundred thousands fled Bhutan between 1990 and 1994. According to United Nation's High Commission for Refugees (UNHCR)'s statistics (1999), 107,600 Bhutanese refugees have been living in refugee camps in Jhapa and Morang districts of the eastern part of Nepal since then. There is now some hope of their repatriation since Bhutanese and Nepalese government has recently agreed to verify the refugee status and repatriate some of them back

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to Bhutan. It has also been estimated that over 15,000 reside outside the camps in the Indian states of Assam and West Bengal (US Department of State, Bhutan country report, 1997).

1.5 Nepal

Nepal is another small, poor, developing, land-locked, mountainous, Hindu kingdom, sandwiched between India and China with 147,181 square Km area and an estimated population of 22.9 million in the year 2000 (Central Bureau of Statistics, HMG Nepal, 2000). Its per capita income is among one of the lowest in the world. Geographically Nepal is divided into three regions: the northern mountainous region, middle hilly region and the southern plane land known as Terai region. However, for administrative purposes, the country has been divided into five regions and 75 districts. Jhapa and Morang districts in the planes, where the Bhutanese refugees are currently living, are one of the most densely populated districts of Nepal.

Nepal is a multiethnic and multicultural country. There are 58 different ethnicity and 32 languages spoken all over the country (Central Bureau of Statistics, Statistical year book of Nepal, 1999). The official language is Nepali, which is spoken as mother tongue by 60% of its people, and is understood by most of the people. The Bhutanese refugees speak the same Nepali language with a little bit different dialect.

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Only one doctor is available for every 15,000 people living in Nepal. Furthermore, health indicators such as infant mortality rate of 64 per 1000, and crude birth rate of 34 per 1000 demand better health services (Central Bureau of Statistics, HMG Nepal, 2000). Regarding mental health services, there are currently a very few psychiatrists with only one mental hospital in the capital. The mental health services for the whole country is thus limited in spite of the high prevalence of mental illnesses, as one-quarter of patients attending two primary settings in Nepal were found to have psychiatric disorders (Wright et. al., 1989). Thus, with existing infrastructure and limited resources, Nepal has difficulties to provide mental health services to the large number of Bhutanese refugees.

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1.6 Our study

A study of mental health and disability among these Bhutanese refugees may contribute to fill the big need of such studies among refugees living in the developing world. Thus, we first carried out an epidemiological survey to determine the occurrence of mental disorders and disability by using standard instruments designed by WHO. We later collected qualitative data by means of focus group discussion and narrative writing to explore knowledge, attitude, and practices (KAP) regarding mental illness and disability and to better understand the association between the two. This thesis is based upon the two

aforementioned studies among Bhutanese refugees living in Nepal. The aim of our study was as follows.

1.6.1 General objective

- To assess knowledge, attitude and practices about mental illness and disability, and investigate the predictors of disability in physically tortured and matched non-tortured Bhutanese refugees living in Nepal

1.6.2 Specific objectives

- To assess knowledge, attitude and practices about mental illness and disability among Bhutanese refugees living in Nepal

- To compare the level of disability between tortured and non-tortured Bhutanese refugees living in Nepal.

- To identify predictors of disability among Bhutanese refugees living in Nepal.

- To investigate the comorbidity and disability among Bhutanese refugees living in Nepal

2.0 LITERATURE REVIEW

A search was carried out for scientific publications in the field of refugee, mental health and disability, and people's perception of mental illness and disability. The literature review is as follows.

2.1 Trauma and psychiatric disorders

Trauma and disaster are parts of our everyday lives, despite our wishes (Ursano et al, 1994), and refugees are exposed to more traumas than are a general population. Several studies involving traumatised refugees from different countries have revealed a high prevalence of mental disorders such as posttraumatic stress disorder (PTSD), affective disorders, and disscociative symptoms (Goldfeld et al, 1988; Kinzie et al, 1990; Hauff & Vaglum, 1995; Shrestha et al, 1998). Studies should also concentrate on the after effects of torture (Lavik et al, 1996) and psychopathology in refugee's life and activities in exile.

2.2 Refugees, psychopathology and disability

The relationship between psychiatric distress and disability in communities devastated by mass violence has received little attention, despite the widespread knowledge that mental illness is a leading cause of disability worldwide (Murray & Lopez, 1996). Only one study (Mollica et al, 1999) so far has been done in the field of refugees, mental illness and disability. This study was carried out among Bosnian refugees living in Croatia to determine the risk factors for disability such as demographic characteristics, trauma, health status and psychological illness. It was a cross sectional survey with sample size of 534 refugees, conducted in 1996 with the use of Hopkins Symptom Checklist 25 (HCL-25), and Harvard Trauma Questionnaire to measure depression and PTSD respectively. Disability measures included Medical Outcome Study Short Form-20 (Stewart et al, 1988), a physical functioning scale based on WHO criteria, and self-reports of socio-economic activity, levels of physical energy, and perceived health status.

The study found that the prevalence of depression and PTSD among Bosnian refugees was 39% and 26% respectively with 20% comorbidity for both the disorders. The disability was found among 25% of the total sample, and those refugees with symptoms comorbid for depression and PTSD were associated with an increased risk for disability compared with asymptomatic refugees. Older age, lack of education, and chronic medical illness were also associated with disability while gender, cumulative trauma, and torture experiences were not associated with increased risk of disability. This study used neither any controls nor structured interviews. Furthermore, these analyses with refugees living in the west, are worth conducting in any other data set.

Another study, though not with refugees, was among ethnic Albanians in Kosovo (Cardozo et al, 2000) on a sample of 1358 people immediately after the war. The instruments used were General Health Questionnaire 28 (GHQ-28), Harvard Trauma Questionnaire, and the Medical Outcomes Study Short-Form 20 (MOS-20) (Stewart et al, 1988) to measure non-specific psychiatric morbidity, PTSD and social functioning respectively. The study found that populations at risk for poor social functioning were living in rural areas, were unemployed, or had a chronic illness. Similarly, in a prospective study among Vietnamese

refugees living in Norway, 15% of the respondents (n=145) reported reduced activity during the last 2 weeks (Hauff & Vaglum, 1997).

2.3 Studies among general population

There have been several studies among general population to see an association between psychiatric disorders and disability. One of them (Berardi et al, 1999) has tried to see the association between psychiatric disorders, medical comorbidity and impairment in mental and physical function in primary care attendees (n= 323) and found that impairment associated with mental disorders was greater than that associated with physical illnesses. Similarly, WHO collaborative study (Ormel et al, 1994) on psychological problems in primary health care facilities in 14 countries (n= 5447) revealed that disability was more prominent among patients with major depression, generalised anxiety, panic disorder, and neurasthenia even after controlling for physical diseases. Moreover, a dose-response relationship was found between severity of mental illness and disability. Results were consistent across disability measures and across cultures.

2.4 Comorbidity and disability

Comorbidity among psychiatric disorders and with physical disorders has been an established fact by very many studies. Kessler (1999, 1994) in his series of articles on comorbidity studies has shown high comorbidity among different psychiatric illnesses, which we too are interested to look at with respect to disability. He found that comorbid generalised anxiety disorder (GAD) and major depression disorder was associated with more impairment than pure disorder. In addition impairment of pure GAD was equivalent in magnitude to impairment of pure major depression, which is inconsistent with the conclusion of Olfson et al. (1997), and Schonfeld et al. (1997) in primary care samples where pure GAD was not associated with significant impairment. Thus, the inconsistency of the results suggests that this issue should be re-examined in other available data sets.

Furthermore, the 1994-1995 National Health Interview Survey (Druss et al, 2000) of disability among 106,573 adults showed that mental disorder (1.1%), general medical (4.8%), and combined conditions (1.2%) were associated with functional disability. Another survey among young adults (n= 3021) showed that the comorbidity was substantial and was significantly related to greater reduction in work productivity and increased rates of professional help seeking behaviour (Wittchen et al., 1998).

2.5 Controlled study of torture survivors

The systematic study of the effects of torture among refugees has, however, been difficult, largely because of problems in organising controlled studies involving randomly sampled torture survivors. Most studies have not been able to involve any control group because of difficulties in finding non-tortured participants of the same age, gender, asylum status, and ethnicity as the participating torture survivors. Moreover, except for one study (Shrestha, et al, 1998), no controlled studies have been carried out on refugees torture survivors in a developing country setting. However, Basoglu et al. (1994), in Turkey, succeeded in soliciting two closely matched groups: one group of 55 tortured political activists and one matched control group of 55 non-tortured political activists with otherwise similar life experiences and found more PTSD, depression, and anxiety symptoms among the torture survivors.

2.6 Study among Bhutanese refugees

The only one study (Shrestha et al., 1998) carried out in 1995 among Bhutanese refugees living in Nepal was a case-control survey to see the impact of torture on a random sample of 526 tortured and 526 non-tortured refugees, matched for age and sex. The main outcome measures used in that study were the Diagnostic and Statistical Manual of Mental

Disorders, Revised third edition (DSM-III R) criteria for PTSD and the HCL-25 for depression and anxiety. The study itself was unique in that it involved random sampling, a matched control group, large sample size, as well as a developing country context. The study found that with the exception of sleep disturbances, the tortured refugees as a group, suffered more on each of the DSM-III-R PTSD symptoms. Significantly more tortured cases were symptomatic of clinical anxiety and clinical depression. The tortured refugees presented more musculo-skeletal system and respiratory system-related complaints than the matched controls. Thus, PTSD symptoms are likely part of a universal reaction to torture. However, that study was limited in scope, focusing on few variables and on symptomatology rather than on diagnosed disorders.

We conducted a follow-up study in the same sample to investigate the predictors of torture status and demographic correlates of the psychiatric disorders, with more improved and refined methodology. We found that among Bhutanese refugees, torture survivors had higher lifetime and 12-month rates of ICD-10 psychiatric disorders. With the exception of male sex, torture status was not associated with demographics. Risk ratios show that tortured refugees (n=418), compared to non-tortured refugees (n=392), are more likely to report recent (within previous 12 months) ICD-10 posttraumatic stress disorder (PTSD), dissociative (conversion) disorders), and persistent pain disorder. Furthermore, the study detected very high prevalence of lifetime (73%) and 12 months PTSD (43%) among torture survivors. Persistent pain disorder was the most common disorder among non-tortured refugees with lifetime and 12 months prevalence rates of 29% and 28% respectively. Eighty eight percent of the tortured and 56% of non-tortured refugees had one lifetime disorder while 74% of the tortured and 48% of non-tortured refugees had one 12 months disorder indicating high psychopathology among this population. Concerning the issue of comorbidity, approximately 3 out of 4 respondents with lifetime PTSD diagnosis in both the groups reported comorbid disorder. Highest comorbidity of PTSD was found with persistent pain in tortured group whereas the same was with specific phobias in non-tortured group (Van Ommeren et al, 2001).

2.7 Rationality of our research

Despite the several studies on psychiatric morbidity and comorbidity, only few studies have included the measurement of disability as their outcome measures. It is still unanswered to what extent the refugees living in the developing countries such as Bhutanese refugees (torture survivors and non-torture survivors) suffer from psychiatric comorbidity and disability over and above other refugees. In addition to psychiatric morbidity, other factors associated with disability are equally important to be explored in such a population so that disability could be predicted. Such knowledge would be of great help to plan for their effective rehabilitation.

2.8 Concepts and understanding of mental illness

Diagnosing psychiatric disorders and associated disability through epidemiological surveys may not always be enough to understand the disorder in totality. Each illness has got some meaning and such type of meaning is worth examining. As argued by Kaplan (1999), it is important to understand the meaning of the phenomenon in that particular culture. While using CIDI's probe flow chart, we observed that Bhutanese refugees could not attribute their symptoms to physical and psychological causation, thus the chart had to be modified as discussed elsewhere in details (Van Ommeren, 2000). This experience signifies the need to understand their way of understanding and explanation for mental illness. Thus, knowledge, attitude and practices about mental illness and associated disability is a topic to be examined in this population, because it is highly determined by culture and belief systems of the society. Understanding of culture is very important in psychiatric field to plan mental health services effectively (Patel, 2000; Kaplan, 1999). The community definition and understanding of mental illness differs from culture to culture and the single term that could carry the complete meaning of mental illness as in western society is hard to find in many cultures (Patel, 1995). Similarly, people have variety of explanation for causation of mental illness. A belief system that mental illness is caused by causes in and around supernatural world is quite prevalent especially in developing countries (Kaplan, 1999; Patel, 1995). Furthermore, belief system also determines the help seeking behaviours for mentally ill people (Kaplan, 1999).

There is evidence to indicate that through examining the particular significance of a person's illness, it is possible to break the vicious cycles that amplify distress. The interpretation of illness meanings can also contribute to the provision of more effective care (Kleinman, 1988). Kleinman thus argues for the importance of investigation of how cultural meanings and norms influence either the perception and expression of symptoms or therapeutic mechanism.

2.9 Help seeking practices for mental illness

Despite the existence of modern mental health care system in Nepal, consultation with spiritual and traditional healers is still a very common practice for mental disorders (Tausig & Subedi, 1997; Wright et al 1989, 1990; Kaplan, 1999). Furthermore, even people living in highly developed countries seek for alternative health services. A survey carried out among 9,585 respondents in USA showed that 16.5% were using complementary and alternative medicine and 21.3% of them met diagnostic criteria for one or more mental disorders (Unutzer et al, 2000). Similarly, a study among Vietnamese refugees living in Norway showed that 52% of respondents (n=145) had used traditional healing methods in past one month (Hauff & Vaglum, 1997). There is hardly any society that does not seek for alternative help for their health problems, especially for mental health problems.

2.10 Stigma associated with mental illness

Mental illness is highly stigmatised in many societies. The stigma associated with mental illness and disability has received more attention in several articles (Byrne, 1999; Druss et al, 2000). Many people do not want to use health services for mental problems as have been observed in very many societies (Sheikh & Furnham, 2000; Kaplan, 1999, Wright &

Hickingbotham, 1986). Almost 4 out of 5 Vietnamese refugees with psychiatric disorders living in Norway were found not to have been in touch with a primary care physician and none of them were in contact with mental health services (Hauff & Vaglum, 1997). This finding further signifies the non-help seeking behaviour of mentally ill refugees living in the west.

2.11 Disability: perception and stigma

Like mental illness, disability can be highly stigmatised. Ingstad (1995) has mentioned that the concept of disability itself must not be taken for granted as in many cultures, one is unlikely to be perceived to be disabled for simple reason that disability as a recognised category does not exist. In many cultures, disability is a taboo but in a few, it is a blessing. For instance, a disabled war veteran is respected as a hero in Nicaragua (Brunn, 1995). Thus, studies of disability require us to move away from the clinic towards community, where individuals and families live with deficits (Ingstad & Whyte; 1995). The hidden burden, that is burden associated with stigma both due to mental illness and disability is another aspect to be explored by researchers.

2.12 Conclusion

The literature review showed that there is a strong need for research that finds the relationship of torture, mental illnesses and disability along with the knowledge, attitude and practices towards mentally ill and disabled people in the context of developing world where most of the refugees currently live.

3.0 MATERIALS AND METHODS

This section is divided into two different parts. The first and second parts will deal with our quantitative study of 1997 and qualitative study of 2000, respectively.

3.1 QUANTITATIVE STUDY

3.1.1 Study design

Our study was a cross-sectional comparative survey. The comparison was made between Bhutanese refugees who were tortured while in Bhutan and those who were not. Willis & Gonzalez (1988) have concluded that if properly conducted, the survey approach represents an effective method to assess the consequences of trauma experiences.

3.1.2 Study population

This study was carried out among Bhutanese refugees living in five refugee camps located in the Southeast of Nepal. More than 100,000 Bhutanese refugees have been living in these UNHCR supported camps since 1990 (UNHCR, 2000). The Centre for Victims of Torture (CVICT)'s refugee staffs did a hut to hut survey in 1994 and identified 2331 Bhutanese adult refugees who reported a history of physical torture (Declaration of Tokyo, 1975). Nevertheless, all female torture survivors may not have registered themselves due to the cultural stigma associated with rape.

3.1.3 Sampling

In 1995, the centre did a comparative study with randomly selected 526 tortured refugees and a control group of 526 non-tortured refugees. The tortured group was randomly selected from the list of 2331 registered torture survivors. The comparison non-tortured participants were the randomly selected neighbours of the tortured participants. Tortured and non-tortured refugees were matched for age and sex. A difference in age of ten years or fewer was accepted as an age match. Gender was chosen as a matching variable, as more men tend to report torture. Age was chosen as a matching variable, as people of certain age groups may have had a similar chance of having mental illnesses and disability in their lifetimes. The same 526 tortured refuges and 526 non-tortured controls were approached for our follow up study in 1997. All the children and young adults below 21 years were excluded no matter whether they were tortured or not. Those refugees who were in non-tortured list in 1995 and if were found to have been tortured between 1995 and 1997 were also excluded in this study.

Out of 1052 refugees in our sampling frame, we were able to approach 946 (89.9%) refugees between March 20 and July 31, 1997. Out of 946 approached refugees, 879 refugees (92.9%) were interviewed, 32 (3.3%) refused, 20 (2.1%) were out of camp, 4 (0.4%) were not found, 5 (0.5%) had died, and 6 (0.6%) were too disabled by mental or

physical illness to attend the interview. Out of 946 interviews, 20 interviews which were not completed because of mental state problem or deafness and, 49 wrongly approached interviewees which were out of our sampling frame were discarded. The remaining 810 participants (77.0%) consisted of 418 tortured and 392 non-tortured refugees.

3.1.4 Instrumentation

We used the demographic section, and the affective, specific phobias, dissociative (amnesia and conversion), posttraumatic stress, persistent pain and generalised anxiety disorder (GAD) modules of Composite International Diagnostic Interview 2.1 (CIDI). Even though the CIDI could assess both ICD-10 and DSM–IV disorders, we are here reporting only ICD-10 disorders. In affective module, we did not include mania thus affective disorders that CIDI identified were only mild to severe depression. Risk factors assessed for developing psychopathology and disability were sex, age, marital status, education, religion, political activity, current and past illness, time since displacement, and time since torture; the last one was asked only for torture survivors. Disability was measured by World Health Organisation's Disability Assessment Schedule-Short version (WHO DAS-S), a semi-structured questionnaire. The physical examinations and, brief medical history taken by two doctors in our study further complemented the disability measurement by ruling out any physical disability.

3.1.4.1 Composite International Diagnostic Interview (CIDI)

The CIDI has been produced in the framework of a major project undertaken by World Health Organisation and the US Alcohol, Drug Abuse and Mental Health Administration (WHO/ADAMHA Joint Project on Diagnosis and Classification of Mental Disorders, Alcohol and Drug-Related Problems). It is a comprehensive, fully standardised and fully structured diagnostic interview for the assessment of mental disorders according to the definitions and criteria of the International Classification of Diseases (ICD-10 WHO 1990, Diagnostic Criteria for Research) and the American Psychiatric Association's Diagnostic and Statistical Manual (DSM-IV, 1994). The CIDI has been designed for use in a variety of

cultures and in a variety of settings. It is primarily intended for use in epidemiological studies of mental disorders, but it can also be used for other clinical and research purposes (WHO CIDI Manual, 1996).

There have been several studies on feasibility of CIDI in different cultures and the majority of the studies have found CIDI to be a reliable and effective instrument (Booth et al., 1998; Peters et al., 1995; Wittchen et al., 1998; Kiejna et. al, 1998; Andrew et al., 1998; Goldberg, 1997; Compton, 1996, Sandanger et al, 1999), yet some researchers do not fully agree (Cooper et al., 1998; Andrew et al., 1999; Rosenman et al., 1997). The CIDI gives the possibility not only to evaluate the prevalence of mental disorders in general population but also to analyse the comorbidity of disorders in examined persons during their lifetime. Many studies on its reliability have confirmed its reliability, and it is used widely in several countries in epidemiological studies.

3.1.4.2 WHO–Disability Assessment Schedule - Short

Disability was measured with the use of World Health Organisation's Disability Assessment Schedule-Short version (WHO DAS-S). In an attempt to develop standard instrument to measure psychiatric disability, WHO initiated a pilot study in 1976 in seven countries, to explore the applicability, reliability and validity of a set of instruments and procedures for the evaluation of functional impairments and disabilities in a population of patients with potentially severe psychiatric disorders. One of the principal instruments of the collaborative study was the WHO Psychiatric Disability Assessment Schedule (WHO/DAS, 1988). Extensive field trials, and studies in over twenty countries have shown it to be a valid and reliable tool for cross cultural comparison of psychiatric disability (WHO/DAS, 1988). Thus, we decided to use the short version of the same instrument in our study.

The World Health Organisation's Disability Assessment Schedule Short version (WHO DAS-S) is an instrument for assessment and rating of difficulties in maintaining personal care, performing occupational tasks and functioning in relation to the family and the broader social context to mental disorders. The instrument was found to be useful, user-friendly and reasonably reliable for use by clinicians belonging to different schools of psychiatry and psychiatric traditions (Janca et al., 1996).

WHO DAS-S is a semi-structured interview and an interviewer rates the disability for personal care, social function, household activity and occupational activity on a Likert

scale of 0 to 5 after detailed communication with the respondent regarding his activity in past one month. No disability was coded as 0, and minimal and obvious disabilities were coded as 1 and 2 respectively. Similarly coding 3 and 4 meant severe and very severe disability respectively, and finally gross disability was coded as 5.

3.1.4.3 Assignment of disability status

Because the instrument (WHO DAS-S) was not validated for Bhutanese refugees and neither was it used for large epidemiological surveys before, we had difficulty to make a cut off point on disability score. Moreover, CIDI questions also do assess symptom and disorder specific impairment (Kessler, 1999). CIDI asks dichotomous question, "Did the symptom or disorder interfere a lot with your life and activities". For instance, in our data, 15% and 39% of total respondents who had CIDI diagnosis of GAD and pain disorders respectively admitted the impairments in their daily life due to the respective disorders. This rate of impairment detected by CIDI indicates that there is quite a high rate of disability in this population. Thus, we decided to give disability status to all those who even had minor global disability as measured by WHO DAS-S in any of the four domains.

3.1.5 Translation

Seven bilingual trained Nepali translators systematically translated and adapted all the instruments over a 3-months period. A bilingual Nepali physician then independently evaluated the translation. Later focus group discussions were done with two groups of uneducated Bhutanese refugees, who evaluated each translated item for comprehension, and they suggested revisions. Finally, the principal researcher, a western expatriate mental health researcher evaluated one back-translation and another blind back-translation of all items for each type of equivalence. Details about the translation of the instruments have been described elsewhere (Van Ommeren et al, 1999).

3.1.6 Pilot testing

Pilot testing with 20 tortured and non-tortured refugees revealed that the CIDI probe flow chart was not functioning as intended. The CIDI probe flow chart consists of a series of structured questions which is meant to differentiate whether a complaint is probably

psychiatric (i.e., medically unexplained) or not. The flow chart is based on the assumptions that the respondents attribute their symptoms to mental, physical, or substance-related processes, and that local doctors have previously communicated their diagnoses to their clients. Both these assumptions appeared not to work in the local context, because doctors hardly communicate their diagnosis to their clients and mostly illiterate respondents could not attribute the cause for their illness. Thus, the lay interviewers could not get enough help from the flow chart to differentiate whether a symptom was due to physical illness or probably due to psychiatric illness. Thus, physicians administered the CIDI section C covering somatoform symptoms, which has to use Probe flow chart all the time. The physicians applied their knowledge and experience of medicine to inquire beyond the structured flow chart questions, and then accordingly coded whether the symptoms were medically unexplained (Van Ommeren et al, 2000).

3.1.7 Data collection procedure

Our survey was through face to face interview because our respondents were mostly illiterate. This kind of interview also provided opportunity for the clarification of questions as people find very difficult to understand and answer mental health related questions. We anticipated the challenge of female respondents experiencing cultural barriers to answering private questions related to sex. Thus, we had female interviewers for all the female respondents. The interviewers were the same team of translators consisting of two male physicians as well as three male and two female undergraduate students. They received three weeks of training in administration of the instruments. The principal researcher, who had previously been trained by a WHO-designated CIDI trainer, conducted the first week of training in administering the CIDI. During the second week, the pilot interviewers tested the questionnaires and it was then extensively discussed with the principal researcher. The WHO-designated trainer conducted the final week of training.

The interviews consisted of a medical and a non-medical section. The medical section, administered to all participants by one of the two physicians, consisted of the somatoform and dissociative disorders section of the CIDI, medical history, WHO DAS-S and a brief physical examination. The five lay interviewers administered the other instruments. This non-medical interview always preceded the medical interview. All interviews took place in the confidential environment of CVICT clinic. The respondents were brought to the clinic by our social workers and counsellors and each interviewer used to take 2-3 interviews a day. The interviewers were not blinded with regard to torture status.

3.1.8 Data handling

To ensure that all the interview books have been filled properly, two doctors edited the interview books right after interviewers finished the interview. If something was missing or left blank, lay interviewers were immediately asked to re-interview his or her respondent and complete it accordingly, because they were available through out the day.

The completed interview books were stored first in our regional office and then transferred to the central office on weekly basis. In addition, there was regular supervision by the mental health researcher from time to time to the field office. Data were entered into computers after completion of the study by two of the five interviewers and were later verified. All the interview books are currently preserved safely at CVICT central office in Kathmandu.

3.1.9 Statistical analysis

We used Chi square and student "t" tests to see the differences in disability between the two groups for the categorical and continuous variables respectively. Associations between disability and all other possible risk factor variables were sought by calculating Odd's ratios using logistic regression analysis. The level of significance for all the analysis was set at $p<0.05$. Univariate logistic regression analysis was carried out for tortured and non-tortured groups separately. Predictors of disability were identified from multivariate logistic regression analysis by using disability as a dichotomous variable. The model was built up by entering all those variables that had significant or close to significance association ($p<0.25$) with disability in univariate analysis (Hosmer & Stanley, 1989). All the data were entered and analysed in Statistical Package for the Social Sciences (SPSS) 9.0 version.

3.2. QUALITATIVE STUDY

The quantitative survey was complemented by a qualitative study, which was aimed to identify the refugee's knowledge, attitude and practices (KAP) about mental illness and disability.

3.2.1 Study population

This study was also done in the same refugee population and the respondents were taken from the same sampling frame of our past quantitative study as far as possible. This study also included several other key informants.

3.2.2 Data collection techniques

We combined different ways of data collecting for this part of the study because of the way that they can complement each other.

3.2.2.1 Focus group discussion

Focus group discussion (FGD), a well-established and widely used tool (e.g. Krueger, 1994) for qualitative research, was used to extract information about disability and mental illness in Bhutanese refugee context. We were interested to know how these people perceive mental illness, disability and associated stigmas. Six separate FGD were conducted with mentally ill and disabled people, their close family members and traditional healers.

3.2.2.2 Case studies / narratives

Case studies involved detailed investigations of a few mentally ill and disabled refugees. I myself interviewed eight refugees having diagnosed psychiatric disorders. It was not a detailed psychiatric case study but a narrative study to illustrate their background history, illnesses, mode of treatment, current status, associated disability and stigma and, torture if they had received. Similarly two cases of physical disability were interviewed to know the nature of disability and stigma associated with it.

3.2.2.3 Selection of participants

Focus group discussion was done with six separate groups consisting of: (a) 8 mentally ill or physically disabled men, (b) 6 mentally ill or physically disabled women, (c) 10 male

family members of mentally ills or disabled persons, (d) 6 female family members of mentally ills or disabled persons, (e) 8 male traditional healers (*dhami, jhankri, bijuwa*), and (f) 2 male and 2 female traditional healers (*dhami, jhankri, bijuwa*). We had approached 10-12 participants for each FGD but not all were available and willing to come to our clinic.

The mentally ill persons were selected randomly from CVICT's database of people with CIDI diagnoses (Van Ommeren et al, 2001) whereas the physically disabled were called from their neighbouring huts. Third and fourth groups were family members of mentally ill and or disabled people. They were mostly spouses and parents who were very much involved in providing care and support to ill and disabled members at home. None of the family members themselves had diagnosed mental illness or disability. The fifth and sixth focus group discussions were done with 8 and 4 traditional healers from the refugee camp selected randomly from a list of 25 such healers; the second group had 2 female participants. We planed to run all these FGDs with males and females in separate groups. Because of the gender roles in society, many women feel awkward to communicate in front of men. However, since we could not get sufficient number of female traditional healers, one group mixed up of males and females.

Similarly 10 narratives were taken from mentally ill and disabled refugees, 6 of them were participants of the focus group discussion. Two out of 10 were physically disabled and three were non-tortured refugees while the rest were tortured cases. The aim of this narrative was to illustrate their significant life events, the way they became refugee and their illnesses and stigmata associated with it. Thus, narratives are not full psychiatric case notes but rather general illustrative narratives.

3.2.3 Data collection

A medical doctor who had never been involved in the treatment of these refugees was the moderator in all focus group discussions. A university psychology lecturer was recruited as

a research assistant to note down and facilitate the FGDs. Both had prior experience of running FGDs. The aims and guidelines of the research were discussed in details with the researcher for one day before collecting data.

A previous refugee community health worker of CVICT was hired to co-ordinate with the camp authority and to bring clients to our clinic. All FGD and interviews took place in the confidential environment of CVICT's Biratnagar Clinic, not far from the camp.

All the FGD were conducted in a room of our clinic with U-shaped chair arrangement in July 2000. All the FGDs were recorded in tapes and in the mean time the research assistant made notes during the discussion. Each focus group discussion was in Nepali language and lasted for about 90 to 120 minutes. One focus group discussion was held each day. All the participants were provided free lunch for that day. The tapes were listened at the end of the day. I myself interviewed and prepared all case studies. All the field activities and progress were informed to the supervisor in Norway and collaborating centre.

3.2.4 Data handling

I was the moderator of FGD and edited the finding at the end of each day. I first used to list up the findings of FGD and checked if something that had been intended to measure was missing. If so, it was then included in the next day's session. Similarly some of the things, which needed elaboration and clarification were considered for the next day's session of focus group discussion. All the collected information, including the audiocassettes, has been preserved.

3.2.5 Data analysis

In case of studies like this, partial analysis usually starts while collecting the data. All the tapes were transcribed and important findings were listed and translated into English. Four

representative case studies will be presented in brief. FGD findings are presented separately for mentally ill and disabled people, their family members, and traditional healers.

3.3 Ethical issues

Because most of our respondents were illiterate, we did not take written consent. We rather took a verbal informed consent after explaining briefly about our research and methods and aims. They were free to choose regarding participation in this study. The consent obtained this way was recorded on paper. We thus followed the Declaration of Helsinki recommendations guiding ethical research (48th World Medical Assembly, Declaration of Helsinki, 1997). Because we were dealing with traumatised people, the interviewees were asked to stop if our questionnaires or discussion appeared to hurt them or trigger their illnesses. Furthermore, free medical check up and treatment including counselling was available to those respondents who needed. All the interviews were conducted in confidential environment and respondents were assured of its confidentiality. Moreover, ethical clearance was taken from Nepal Health Research Council and also from the Norwegian Ethical Committee for our qualitative study.

4.0 RESULTS

4.1 RESULTS OF THE QUANTITATIVE STUDY

The study was carried out among 810 adult Bhutanese refugees aged between 21 and 85 years. Almost 68% of the respondents were illiterate and 90% of them were married. Four fifth of the respondents were Hindus and rest were either Buddhist or Christians. The tortured (418) and non-tortured (392) groups in the sample were similar in terms of age with the mean age of 44.5 years (SD 12.4) and 44.1 years (SD 12.6) respectively. This is consistent with the design of our study as the two groups were matched for age. Of the total participants, 75% and 78% were males in non-tortured and tortured groups respectively, thus less than one quarter in both the groups were females. It was found that the significantly more tortured refugee were Hindus (84% vs. 76%, p=0.008) and similarly more Buddhists were in non tortured group (19% Vs 11%, p=0.004). More on the non-tortured group reported current illness during the interview (37% Vs 27%, p=0.002), because torture survivors had better access to health services. Otherwise, the two groups were similar in terms of marital status, employment status, education, and past illness.

Among the tortured group, 51.0% reported having persistent pain disorder and 43.3% reported having posttraumatic stress disorder in the last 12 months period. Almost three-quarter reported having any one assessed psychiatric disorder in the same period. On the other hand, persistent pain disorder (27.6%) and specific phobia (25.8%) were most frequently reported psychiatric disorders in the last 12 months period among the non-tortured group with any one psychiatric disorder in half of the sample.

4.1.1 Spectrum of disability

Disability as mentioned earlier was measured for four major functions of an individual on a Likert scale ranging from 0 for no disability to 5 for gross disability. This has been illustrated in details in table 1. We found that the same person who had one form of disability, for instance, social disability, had a tendency to have other kinds of disability such as personal care, social or occupational disability of almost similar grade in both tortured and non-tortured groups. Four out of five respondents had none of the disability in both the groups. Among the disabled refugees, three fourth in both the groups were minimally disabled. Only one in tortured group was severely disabled for his personal care domain.

Table 1
Types and degrees of disability among tortured and non-tortured refugees

Degree of disability	**Social disability** t* (%)	nt*(%)	**Household disability** t*(%)	nt*(%)	**Occupational disability** t*(%)	nt*(%)	**Personal care disability** t*(%)	nt*(%)
No disability	343 (82.1)	318 (81.1)	344 (82.3)	316 (80.6)	342 (81.8)	315 (80.3)	339 (81.2)	310 (79.1)
Minimal	56 (13.4)	49 (12.5)	55 (13.2)	52 (13.3)	59 (14.1)	51 (13.0)	68 (16.3)	61 (15.6)
Obvious	17 (4.1)	25 (6.4)	17 (4.1)	24 (6.1)	14 (3.3)	25 (6.4)	8 (1.9)	20 (5.1)
Severe	2 (0.4)		2 (0.4)		3 (0.8)	1 (0.3)	2 (0.4)	1 (0.2)
Very severe								
Gross							1 (0.2)	
Total	418 (100)	392 (100)	418 (100)	392 (100)	418 (100)	392 (100)	418 (100)	392 (100)

Notes:

t* & nt* stand for tortured and non-tortured groups respectively

4.1.2 Effects of torture on disability

One of the objectives of the study was to compare the detected disability between the tortured and non-tortured group. The comparison for each disability is shown in the following table, where different grades of disability have been added up and presented as disability status for each domain of disability. We found that there was no significant difference in terms of detected disability in all the four domains between tortured and non-tortured group. Moreover, a single variable called *any disability* was created out of four different domains as explained earlier and 21% tortured and 24% non-tortured refugees were found to have *any disability status*. The difference between the two groups still remained non-significant further strengthening the null association between disability and torture status. The tortured and non-tortured group had mean total disability score of 0.9 (SD=2) and 1.0 (SD=2.1) respectively (independent t (808)=0.8; p=0.396). Among the

disabled, only 16% in the tortured and 11% in the non-tortured group were disabled for less than one year and rest were either for one year or longer.

Table 2

Comparison of Disability between tortured and non-tortured refugees

Type of Disability	Tortured *n	%	Non-tortured *n	%	Chi Square	p value
Personal care	79	18.9	82	20.9	0.518	0.472
Occupational	76	18.2	77	19.6	0.282	0.595
Household	74	17.7	76	19.4	0.380	0.537
Social	75	17.9	74	18.9	0.118	0.731
#Any disability	89	21.2	93	23.7	0.687	0.407

Notes

***n is the total number of people with disability including minimal disability.**

Chi square values were calculated with 1 degree of freedom.

Any disability means at least one of the four disabilities detected by the instrument.

4.1.3 Relationship of disability with socio-demographic, torture and medical history variables

Associations with disability as a dependent variable were sought for different background variables. Odds for disability were calculated by using univariate logistic regression analysis for socio-demographic, torture and medical history variables that were considered as possible risk factors for developing disability. For this purpose, we needed disability as a dichotomous dependent variable, which was created by making cut off between 0 and 1 out of the total disability score. This gave disability status for those who were hampered at any degree in performing either their social, or personal, or occupational or family roles. The table below illustrates the Odds of being disabled and 95% confidence intervals for several personal characteristics, both among tortured and non-tortured groups.

Table 3

Association between disability and socio-demographic and personal variables

Variables	Tortured refugees (418)					Non-tortured refugees (392)				
	Total	Disability n	%	OR	CI	Total	Disability n	%	OR	CI
Age in years										
21-35	119	18	15.1	1		113	23	20.4	1	
36-54	207	45	21.7	1.5	0.8-2.8	207	45	21.7	1.1	0.6-1.9
55-85	92	26	28.2	2.2	**1.1-4.3**	72	25	34.7	2.1	**1.1-4.1**
Sex										
Male	324	61	18.8	1		292	58	19.9	1	
Female	94	28	29.7	1.8	**1.1-3.1**	100	35	35.0	2.2	**1.3-3.6**
Marital stat.										
Married	379	78	22.6	1		349	83	23.8	1	
Others	39	11	28.2	1.5	0.7-3.1	43	10	23.3	0.9	0.5-2.0

LWS No Yes	42 376	12 77	28.6 22.4	1.5 1	0.7-3.1	45 347	12 81	23.3 26.7	1.2 1	0.6-2.5
Education No Yes	284 134	73 16	25.7 11.9	1 0.4	**0.2-0.7**	264 128	73 20	27.7 15.6	1 0.5	**0.3-0.8**
Religion Hindu Others	349 69	80 9	22.9 13.0	1.9 1	0.9-4.1	298 94	74 19	24.8 20.2	1.3 1	0.7-2.3
Pol activity No Yes	292 126	69 20	23.2 15.8	1 0.6	0.3-1.0	246 146	65 28	26.4 19.2	1 0.7	0.4-1.1
Eco. Status Low/average High	290 128	64 25	22.1 19.5	1.1 1	0.6-1.9	292 100	69 24	23.6 24.0	1.0 1	0.6-1.7
Employment Yes No	31 387	6 83	19.4 21.4	1 1.1	0.4-2.8	27 365	1 92	3.7 25.2	1 8.7	**1.2-64.7**
Current illness No Yes	305 113	49 40	16.0 35.3	1 2.8	**1.7-4.6**	247 145	36 57	14.6 39.3	1 3.8	**2.3-6.2**
Past illness No Yes	311 107	54 35	17.3 32.7	1 2.3	**1.4-3.8**	272 120	48 45	17.6 37.5	1 2.8	**1.7-4.5**
Time since displacement 1-5 years 6-8 years	277 141	57 32	20.6 22.7	1 1.1	0.7-1.8	213 179	53 40	24.9 22.3	1 0.9	0.5-1.4
Time since torture 1-6 years 7-10 years	245 173	52 37	21.2 21.4	1 1	0.6-1.6	NA	NA	NA	NA	NA

(Table 3 continued)

Notes:
NA stands for not applicable and LWS means Living with spouse.
OR and CI stand for Odd's ratio and 95% Confidence Interval respectively.
Pol. Activity = Political activity, Eco. Status = Economic status, Marital stat. = Marital status.
Significantly associated variables ($p<0.05$) are highlighted at corresponding Confidence Intervals.

We found that female gender carried almost twice more risk of disability than males both for tortured and non-tortured refugees (OR 1.8, CI 1.1-3.1; OR 2.2, CI 1.3-3.6 respectively). Similarly, as one would expect, the respondents in the older age groups were found to be more disabled than those in younger age groups. There were no associations seen in both the groups between disability and marital status, economic status, religion, and

political activity. However, having education in both the tortured and non-tortured groups appeared to be a protective factor for disability compared with those who were illiterate (OR 0.4, CI 0.2-0.7; OR 0.5, CI 0.3-0.8 for tortured and non-tortured respectively). Those who had present physical illness in both the groups were also seen to have more chances for disability (OR 2.8, CI 1.7-4.6; OR 3.8, CI 2.3-6.2 for tortured and non-tortured refugees respectively). Similarly, disability was significantly more among those tortured and non-tortured refugees who had some physical illness in the past (OR 2.3, CI 1.4-3.8; OR 2.8, CI 1.7-4.5 respectively). On the other hand, torture related variables such as time since torture, and time since displacement did not bear any association with disability among tortured refugees. Except for employment, where the non-tortured unemployed were at more risk for developing disability (OR 8.7, CI 1.2-64.7), the two groups had similar pattern of association with disability.

4.1.4 Relationship between disability and psychiatric illnesses

We had data on 12-months prevalence of (ICD-10) generalized anxiety, post-traumatic, persistent pain, specific phobia, disscociative and depression disorder from CIDI and thus the following associations with disability were calculated among tortured and non-tortured respondents by using univariate logistic regression.

Table 4

Association of disability with 12-months psychiatric disorders

Variables	**Tortured refugees (418)**					**Non-tortured refugees (392)**				
	Total	Disability			OR	**Total**	**Disability**			**OR** **CI**
	n	**n**	**%**	CI			**n**	**%**		
GAD										
No	392	80	20.4	1		370	81	22.9	1	
Yes	26	9	34.6	2.1	0.8-4.8	22	12	54.5	4.3	**1.7-10.3**
PTSD										
No	237	37	15.6	1		376	86	22.3	1	
Yes	181	52	28.7	2.2	**1.3-3.5**	16	7	43.8	2.6	0.9-7.2
Persistent pain disorder										
No	205	31	15.1	1		284	54	19.4	1	
Yes	213	58	27.2	2.1	**1.3-3.4**	108	38	35.2	2.3	**1.4-3.7**

Specific phobia										
No	326	56	17.1	1		291	56	19.2	1	
Yes	92	33	35.8	2.6	**1.8-3.7**	101	37	36.6	2.3	**1.5-3.6**
Dissociative disorder										
No	343	61	17.7	1		379	86	22.7	1	
Yes	75	28	37.3	2.7	**1.6-4.7**	13	7	53.8	3.4	**1.3-12.2**
Depression										
No	386	78	20.2	1		372	84	22.6	1	
Yes	32	11	34.3	2.1	**1.0-4.5**	20	9	45.0	2.8	**1.1-7.0**
Any disorder										
No	107	11	10.2	1		204	28	13.7	1	
Yes	311	78	25.0	2.9	**1.5-5.7**	188	65	34.6	3.3	**2.1-5.5**
# of disorder										
No disorder	107	11	10.3	1		204	28	13.7	1	
1-3 disorder	149	23	15.4	1.6	0.7-3.4	68	21	30.9	2.8	**1.5-5.4**
4-6 disorder	162	55	34.0	4.5	**2.2-9.1**	120	44	36.7	3.6	**2.1-6.3**

Notes:

GAD is generalized anxiety disorder and PTSD is posttraumatic stress disorder.

OR and CI stand for Odd's ratio and 95% Confidence Interval respectively.
# of disorder stands for number of disorders.
Significantly associated variables ($p<0.05$) are highlighted at corresponding CI.

Except for GAD among torture survivors and PTSD among non-torture survivors, there was significant association seen between disability and all other assessed psychiatric disorders. We could find an association between disability and PTSD only among tortured refugees (OR 2.2, CI 1.3-3.5). Similarly, an association of disability with GAD was significant only in the non-tortured group (OR 4.3, CI 1.7-10.3). There was also a dose response association seen with the number of disorders; the more the disorders, more the odds of disability. Such an association was more obvious among the non-tortured refugees.

4.1.5 Comorbidity with PTSD and effects on disability

Another objective was to look for comorbidity between PTSD and other mental disorders and examine its effects on disability. Out of 418 tortured refugee, 181 were diagnosed as cases of 12-months posttraumatic stress disorder by CIDI and the following table shows its comorbidity with other disorders and their association with disability.

Table 5
Comorbidity between PTSD and 12-months mental disorders among torture survivors and effects on disability

Comorbidity with	**Disability n**	**%**	**Odd's Ratio**	**95% Confidence interval**	**p value**
Total PTSD (181)	52	28.7	**NA**	NA	**NA**
GAD					
No (167)	45	26.9	1		
Yes (14)	7	50.0	2.7	0.9-8.2	0.761
Persistent pain					
No (72)	15	20.8	1		
Yes (109)	37	33.9	1.9	0.9-3.9	**0.049**
Specific phobia					
No (132)	29	22.0	1		
Yes (49)	23	46.9	3.1	1.6-6.3	**0.013**
Dissociative disorder					
No (139)	33	23.7	1		
Yes (42)	19	45.2	2.5	1.2-5.0	**0.011**
Depression					
No (159)	44	27.7	1		
Yes (22)	81	36.4	1.5	0.6-3.8	0.40

Among the tortured refugees, it was seen that having PTSD together with either persistent pain or specific phobia or dissociative disorder increases the risk of disability. On the other hand, there was no association seen between disability and comorbidity of PTSD with depression and generalised anxiety disorders.

4.1.6 Predictors of disability

After having univariate analysis done, we wanted to control for confounding variables to determine the possible predictors of disability. Thus, all the variables having significant ($p<0.05$) or close to significant association ($p<0.25$) with disability in our univariate analysis, were entered into the logistic regression model as independent predictor variables of disability. We also checked Spearman's correlation coefficient between those variables entered in the model to see if they had strong association with each other (i.e., multicollineaity) and it was found that none of the pair has the coefficient value more than 0.80. The variables of interest entered simultaneously in multivariate analysis for tortured group were gender, age, education, religion, marital status, political activity, present and past physical illness, PTSD, GAD, persistent

pain, specific phobia, dissociative, and depressive disorders. Religion and marital status were omitted but employment status was added while performing multivariate analysis for non-tortured group.

Table 6

Multivariate analysis with logistic regression module

Variables	Tortured refugees (418)					Non-tortured refugees (392)				
	Total	Disability			AOR	Total	Disability		AOR	CI
		n	%	CI			n	%		
Age in years										
21-35	119	18	15.1	1.0		113	23	20.4	1	
36-54	207	45	21.7	1.6	0.8-3.2	207	45	21.7	1.0	0.4-2.0
55-85	92	26	28.2	1.9	0.9-4.2	72	25	34.7	2.3	**1.1-5.1**
Sex										
Male	324	61	18.8	1		292	58	19.9	1	
Female	94	28	29.7	1.2	0.6-2.6	100	35	35.0	1.0	0.5-1.9
LWS										
No	42	12	28.6	0.9	0.4-2.2					
Yes	376	77	22.4	1		NA	NA	NA	NA	NA
Education										
No	284	73	25.7	1		264	73	27.7	1	
Yes	134	16	11.9	0.6	0.3-1.1	128	20	15.6	0.6	0.3-1.3
Religion										
Hindu	349	80	22.9	2.2	0.98-4.8					
Others	69	9	13.0	1		NA	NA	NA	NA	NA
Pol activity										
No	292	69	23.2	1		246	65	26.4	1	
Yes	126	20	15.8	0.8	0.4-1.5	146	28	19.2	0.9	0.5-1.6

Employment Yes No	NA	NA	NA	NA	NA	27 365	1 92	3.7 25.2	1 7.1	0.8-59.8
Current illness No Yes	305 113	49 40	16.0 35.3	1 2.0	**1.1-3.8**	247 145	36 57	14.6 39.3	1 2.9	**1.7-5.2**
Past illness No Yes	311 107	54 35	17.3 32.7	1 1.3	0.7-2.5	272 120	48 45	17.6 37.5	1 1.6	0.9-2.8
GAD No Yes	392 26	80 9	20.4 34.6	1 1.1	0.4-2.9	370 22	81 12	22.9 54.5	1 3.3	**1.2-9.3**
PTSD No Yes	237 181	37 52	15.6 28.7	1 2.0	**1.2-3.5**	376 16	86 7	22.3 43.8	1 2.2	0.6-7.2
Persistent pain disorder No Yes	205 213	31 58	15.1 27.2	1 1.4	0.8-2.4	284 108	54 38	19.4 35.2	1 1.3	0.7-2.4
Specific phobia No Yes	326 92	56 33	17.1 35.8	1 2.2	**1.2-3.8**	291 101	56 37	19.2 36.6	1 1.6	0.9-2.8
Dissociative disorder No Yes	343 75	61 28	17.7 37.3	1 1.4	0.7-2.8	379 13	86 7	22.7 53.8	1 1.5	0.4-5.4
Depression No Yes	386 32	78 11	20.2 34.3	1 0.9	0.4-2.4	372 21	84 9	22.7 53.8	1 1.4	0.5-4.3

Notes:
AOR and CI stand for Adjusted Odd's ratio and 95% Confidence Interval respectively.
Significantly associated variables ($p<0.05$) are highlighted at corresponding Confidence Intervals.

GAD is generalized anxiety disorder and PTSD is posttraumatic stress disorder.

NA = Not applicable, Pol activity = Political activity, LWS = Living with spouse.

Out of the 14 variables simultaneously entered in the model for tortured refugees, three predicted disability. Thus, the table shows the increased odds of disability for tortured refugee if they had current illness (OR 2.0, CI 1.1-3.8), or PTSD (OR 2.0, CI 1.2-3.5) or specific phobia (OR 2.2, CI 1.2-3.8), after controlling for age, sex, education, religion, marital status, past physical illness, and generalized anxiety, persistent pain, dissociative and depression disorders.

On the other hand, a separate multivariate analysis with 13 different variables for non-tortured refugees showed that the predictors were somewhat different from the tortured group. Except for the present illness (OR 2.9, CI 1.7-5.2) two new predictors, generalized anxiety disorder (OR 3.3, CI 1.2-9.3) and older (>55 years) age (OR 2.3, CI 1.1-5.1) were found to have an association with disability after controlling for sex, education, political activity, marital status, past physical illness, and PTSD, persistent pain, dissociative, specific phobias and depression disorders.

4.2 RESULTS OF THE QUALITATIVE STUDY

4.2.1 FOCUS GROUP DISCUSSION

General findings

The participants in the six FGD were aged between 20 and 60 years, and 14 out of 42 were females. They were mostly either illiterate or had acquired basic literacy through informal education, and they all had farming as their main occupation while in Bhutan. None of the participants were closely related, except in one group where there were two brothers. They all were living close to each other, and thus they knew each other beforehand. They all were of similar socioeconomic status at least in their refugee situation. They all were quite excited to come to our clinic because they hardly can afford to be out of the camp. In all the groups, a few people were quite talkative, and thus they were dominant while others were passive, therefore, the moderator had to probe these others quite frequently. People usually had a tendency to agree with what former participant had stated.

All the participants were informed what they were supposed to discus about. They were also told about the passive role of the moderator and assistant. As suggested by Krueger (1994), the moderator tried to be non-directive as far as possible. But we realized that this was not fully possible in this context. Most of the time, we felt that it was a group interview, and individuals in the group were responding directly to the moderator. The moderator had to remind the group quite often that they should discuss among themselves. Eye contact of the participants was with the moderator and facilitator most of the time.

4.2.1.1 FGD WITH MENTALLY ILL AND DISABLED REFUGEES

We did FGD with male and female groups separately and each group included two physically disabled people. The aim of keeping a few physically disabled people in the discussion was to explore their perception of disability both due to physical and mental disorders and associated stigma.

4.2.1.1.1 Mental illness: causes and consequences

For majority of the participants, mental illness meant madness, and they said that it appears because of absolute lack of thoughts or change of thoughts or loss of memory power. A few disagreed and argued “We are mentally ill but not mad so one does not have to be mad to be mentally ill”. Worrying and anxiety especially about their future, staying alone quietly, and restlessness were other ways of presentation of mental illness according to them. On contrary to others, a participant in the female group said that madness is not a mental illness. She further explained “Mental illness is due to some problems inside one’s head or chest or soul (*tauko wa man wa mutuko kharabile*) while madness on the contrary is due to problem in one’s brain or mind (*dimagko kharabi*).” She believed that head and brain are

two distinct structures with different functions. Like other people, she was referring to soul as a control center for psychic state of an individual.

Several causes, including torture, refugee life, lack of food and shelter, chronic illnesses, family problems, bad fortunes, love tragedy, and unsuccessful life events, were pointed out as other possible causation for mental illness. Interestingly, both the groups stressed that one of the important causes of mental illness is the spirit met in Jungle known as "*Jangali"*. When *Jangali* possesses someone, it makes him or her faint with convulsions (*behos parcha, murcha parcha*). Furthermore, some participants were of the opinion that chronic non-curable physical illness could lead to mental illness. But, for many of them, mental illness itself appeared as a non-curable disease and they believed that there is cure for physical illness but not for mental illness.

They all agreed that mental illness could lead to significant weight loss, weakness, and disturbances in different roles such as roles in society, family and personal care. "We can not do what we used to do before having these illnesses. Our illness has not only affected us but has also badly affected our family and our children because we can no longer take proper care of them", was unanimously mentioned by mentally ill persons. Some were very frustrated because they have seen some of their friends with similar illness getting completely cured but they did not.

4.2.1.1.2 Disability and its causes

The literal translation of disability in Nepali is "*apanga*" i.e., one with something wrong in any of five senses or absent body organ. When they were asked about disability, they all thought of physical disability and defined it as inability to walk, talk, listen, see or do what normal persons can do. We were initially in trouble because our interest was more on disability due to mental illnesses, and we did not have any other word that could cover all ranges of disability. Luckily, the female group during the discussion came up with two new terms, "*sape bhayeko" and "bimar bhayeko"*. They defined *sape bhayeko* as someone who may look physically normal but can not move. He usually lies down on his bed and is

dependent on others for all his care. They further added that it usually appears at birth, however, it may sometimes appear later in life. The second term *bimar bhayeko* was defined as someone who is sick looking and can not do things, which a normal individual should be able to do. *Bimar bhayeko* is usually associated with any chronic physical or mental illness. Moreover, a participant in the male group said, "Having mental illness is itself a disability as I could not do things properly." Later, all the participants agreed with this after the moderator inquired how they felt about his idea.

Regarding the causes of disability, all were talking about the congenital causes because they assumed that disability mostly appears at birth. However, some participants said that committing sin in own's past life can cause disability in present life because they have belief in reincarnation and "*karma"*. Some also added that if parents commit sin in their present life, their children are likely to born with disability. However, a physically disabled participant disagreed with this idea. Even though his son was born with clubfeet like him, he was quite confident that he did not commit any sin in his life. Other possible causes discussed were lack of nutrition and vitamins, and use of drugs by mother during pregnancy, lack of immunization, lack of sanitation, and lack of medical services. Female group also added that *Jangali* and mental illness could lead to disability. The same group explained, "Some children are born disabled to take back the loan or debt from their parents, which they did not pay in their past life. Some of them die after debt is cleared". Apart from these causes, wounds and accidents were also said to be causes of disability. One shared his experience of ignorant action as a cause of disability. "My neighbor's son had pain in his eyes and his father after chewing some pepper blew into his son's eyes because this is a sort of popular home treatment for such a red and painful eyes. Later, the child totally lost vision and became blind", he illustrated.

4.2.1.1.3 Help seeking behaviors

Both with respect to mental illness and to disability, almost all of them first went to traditional healers and then later to the modern health services. Some still expressed their faith on traditional healers while others did not. Some got worse after seeing traditional healers while others developed adverse effects of allopathic medications. One who disliked

traditional healers told her own experience, "After the healer said that my illness was due to witchcraft, every body around me started to pluck out my hair forcefully with a belief that it would hurt the witchcraft. It was so painful procedure that I was having pain at my head even after three months." Thus, she and some others had less belief on traditional healers but more beliefs on medical personnel and drugs. Some claimed that they spent so much of money to get treatment from healers and were then regretting. Other than this, "We need some work to keep ourselves busy then only we can get rid of our mental illness", said one respondent and later the whole group agreed upon. Some of them believed that they were not sick at all and they only needed some sleeping pills because they found difficulty to fall asleep. Physically disabled did not search any medical treatment because it was since their birth and they thought that there was no cure for it.

4.2.1.1.4 Stigma

"Our family treat us well. They take us to healers or doctors and provide medicines in time." They all said. Even the friends and neighbors behave well with them. But, a few disabled participants said that they are being humiliated. In the beginning, many people come to visit mentally sick and disabled people, and show sympathy but later, fewer people come because they are chronically ill and people do not want to disturb them more. Even then, they sometimes feel sad and worthless. They wonder why they had to suffer like that. "Some people even blame me that I am faking", one female participant said. On the other hand, a female mentally ill respondent shared a real story where a "*sape"* child who was said to have brought all lucks to a neighborhood family. "A baby was born so disabled to her neighbor that he could not move at all after his birth. The parents did not feel any burden, in stead took care of him very carefully because their family prospered after his birth. At the age of five, he passed away and the parents felt so unhappy because their family situation deteriorated onwards", she explained.

Regarding the issue of marriage, some of the respondents had experienced difficulty in establishing marital status, either with them or with their family members. They said that it is worse for persons with disability than for those with mental illness. For those who

developed illness after marriage, the illness had disturbed their marital relationship very much. The groups further added, “If it is a minor disability or minor mental illness, it does not affect in establishing marital relationship”.

4.2.1.1.5 Relation between mental illness and disability

Male group had the opinion that the relation between mental illness and disability may go in either direction. They explained, “Mentally ill person sometimes does not know what he is doing so that he may break his legs and become disabled. On the other hand, disabled people feel sad and frustrated and may develop mental illness. A female participant said,“ Yes, mental illness may cause some sort of disturbances in one’s daily roles but I would not like to call it disability (*apanga*), better term would be “*birami bhayeko”* if the illness has hampered very much”

4.2.1.2 FOCUS GROUP DISCSUSSION WITH FAMILY MEMBERS

We had FGD with 10 men and 6 women separately who were close family members of the mentally ill and disabled refugees. None of them had either diagnosed psychiatric disorders or any disability. They were mostly spouses and parents of the mentally ill or disabled persons.

4.2.1.2.1 Mental illness: causes and consequences

As with the previous groups, mental illness to them simply meant madness even though fainting attacks, abnormal behavior, mental tension, worry and anxiety were said to be other ways of presentation. The male group defined mental illness as an illness resulting from something wrong within

one's body, which makes him incapable to have control over mind and thoughts.

Regarding the causes, some men were of the opinion that only the traditional healers could know the causes and differentiate it from physical illness, and could treat appropriately, while others in the same group disagreed and showed more faith on doctors. Some of the causes brought up during the discussion were refugee experiences and problems, family and economic problems, chronic physical illness, lack of work, lack of nutrition and vitamins, and lack of peace at home. Men also came up with the explanation that position of planets (*graha dasha bigrera*) determines the severity and duration of mental illness. The same group also shared the experience that their ill members have pain in the body that shifts to several parts of their body. "Although many people blame witchcraft for their illness, we have seen that so-called and blamed witches are usually poor, single, and ugly looking woman, and I no more believe in it", said one of the female participants. In this way, she was referring to who are usually blamed as witches in the society.

Female group said that mentally ill people would cause problem in the society only if they are of violent nature. Furthermore, such a person may do harm to his or her own body. They further pointed that mentally ill persons cannot take care of themselves and thus they have to depend on others. The men group also agreed upon these points and added that mental illness could make one very weak, thin, debilitated and could even lead to death. They believed that their family members are living a sort of *bekar* (worthless, useless) life. They could not think of anything worse than a having mentally ill or disabled person in their family.

4.2.1.2.2 Disability and its causes

Their understanding of disability was not different from the groups of mentally ill and disabled people. Apart from congenital causes, a man said, “My daughter was absolutely fine until the age of five years but after having high fever at the age of five, she became deaf”. Both the groups were familiar with the terminology *sape* and *birami bhayeko* as

discussed earlier. They added that bad spirits (*lagan lageko)* could also cause *sape,* especially in early childhood.

So far as the causes of disability were concerned, both the groups said that lack of nutrition both during and after pregnancy, bad *karma* in past life, accidents, stroke, and ignorance could lead to disability. Some in the female group were not aware about the causes but later they agreed with what others brought up during the discussion. The male group also agreed that disability of parents, and high fever in children are other possible risk factors for developing disability.

4.2.1.2.3 Help seeking behaviors

Elicited help-seeking behavior was not distinctly different from the behavior mentioned by the previous groups. Some of them also used herbs for the treatment. Those who are disappointed with medical treatment said, ”What our patients get are sleeping tablets, no thing more than that. These tablets have several side effects. We have felt that there is no cure of their illness even with such medication”. On the

other hand, some strongly believe that medical doctors are the ones who can provide appropriate treatment for their patients and they have realized that the medical treatment usually has to be continued for a long period of time. Regarding the disability of their family members, some did not search for any treatment as it was there since the birth while others tried with all the means such as traditional healers, priest, herbs, and modern medicine, but none of them did any help. These days, they are optimistic because of rehabilitation services in the camp for disabled people.

4.2.1.2.4 Stigma

“Most of the people are sympathetic and help us for proper treatment of our patients but some are not”, both the group agreed. They further said that fewer people come to their houses because of the fear of abnormal behavior by some of their severely mentally ill family members. The female group also mentioned that some neighbors even recommend them to take their patients to police instead of taking to health centers. The male group further added that normal kids of mentally ill or disabled people find difficulty to play

with their friends because they tease them for their parent's illness or disability.

Regarding the issue of marriage, they all said unanimously that some people hesitate to establish marital relation with their families. "Marriage between two disabled persons has been quite a common phenomenon. Similarly, marriage with normal individual is also possible sometimes. Educated people usually do not hesitate to accept such marriages", they expressed. According to the female group, gender also makes difference. They further explained that if disabled or mentally ill or family member of such is a male, there is usually less difficulty to find a normal groom. However, if the disabled or mentally ill person is female, then it is not easy at all.

Both the groups said, "We try all the means to cure them and we love them very much whether they are disabled or mentally ill as they are part of our family. We wish they could be cured completely." All of them had sometimes felt sad and disappointed for not being able to have them cured

despite all the efforts and measures. One frustrated father said, “I sometimes feel that my son should either get rid of his illness or better die of it because I can not see him living like this forever.” A wife of manic man said, “I do not argue with my husband but rather listen what ever he says. That way he calms down.” A sister of visually impaired girl claimed that vision is the most important sense and thus, the worst form of disability in her opinion is blindness.

4.2.1.2.5 Relationship between disability and mental illness

According to them, people with mild mental illness have no problem to accomplish their activities but severe mental illness could lead to disability. “They become lean and thin, and weak after having mental illness, and later, they even can not take care of themselves so we have to do everything for them”, communicated the women group. Men were worried that their mentally ill members may develop total paralysis afterwards.

4.2.1.3 FOCUS GROUP DISCUSSION WITH TRADITIONAL HEALERS

4.2.1.3.1 Mental illness: causes and consequences

Their definition of mental illness was not much different from other groups. As far as the causes were concerned, both the groups stressed more on the supernatural causes. Dead spirits, angry family or other god and goddesses, bad spirits, bad spiritually polluted air, "*Jangali"*, possession, witchcraft were said to be the possible causes of mental illness besides others mentioned in earlier FGD. One said, "Trauma to the body is physical illness and trauma to one's soul (*manko chot*) is mental illness". Others could differentiate physical illness from mental as the former is a wound outside and the latter is wound inside (*bahiarko ghau ra bhitrako ghau*).

Both the groups agreed that mental illness could lead to some sort of disability because mentally ill persons could not accomplish several normal functions as others could. They further added, "Mentally ill people complain of pain every where on their body and later they become thin and weak".

4.2.1.3.2 Disability and its causes

The definition of disability was not very different from other groups. Initially they only meant physical disability but later included *sape* and *bimar bhayeko* as discussed earlier. For some, loss of vision was the most severe form of disability while for others loss of movement was the most severe disability.

Regarding the causes, they were paying more emphasis on supernatural causes even though they claimed that lack of enough nutrition during pregnancy, use of drugs and illness during pregnancy and weakness of nerves could also result in disability. Committing sin in the past life either by oneself or one's older generation, and punishment by God for some misbehavior were other causes of disability said by both the groups.

4.2.1.3.3 Relation between mental illness and disability

Mental illness could lead to disability but they all claimed that they could prevent it by providing the accurate treatment in time.

4.2.1.3.4 Healers' experiences

Healers were keen to tell the group how they had successfully treated their mentally ill clients. They were proudly saying, "We are the ones who can successfully treat them otherwise they will get worse. We traditional healers treated them even at the time when there were no doctors", and "We can treat them in 3 days if doctors need 15 days. The earlier they come, we can find out the cause and cure them". However, some claimed that both doctors and traditional healers are equally responsible and able to treat mentally ill clients. They further described that they have two approaches for treatment. One is called "*Mantra"* that they apply for illnesses caused by supernatural causes. They do all sorts of rituals like worshiping God, sacrificing animals in his name, communicating with God in a trance state, blowing air with special religious words (*fuk fak garne*). They told that *jangali* (jungle ghost illness) can be treated well with this approach. Another approach is *Tantra* that is reserved for physical illness from inside the body or physical symptoms without any specific illness. In this approach, they try to build up the self confidence of their clients by showing them to have something done in their favor, for instance, offering them a cup of water after blowing it with some religious words (*pani matarera khan dine*). They all said that they treat all the clients equally who come to seek help no matter whether they are physically ill or mentally ill or disabled.

4.2.2 NARRATIVE CASE HISTORIES

The following narratives of three mentally ill people and one disabled person illustrates significant life events, the way they became refugees and their illnesses and stigmas associated with it. Comments to each case history are given after the narratives.

Case 1

Mrs. M, a 40-years old, illiterate, married woman, was a farmer in Bhutan. When she came for our interview with the refugee health worker, she appeared to be a cheerful middle aged woman with little anxiety regarding the interview. Because of the full confidence in CVICT, assured confidentiality, and presence of the female refugee worker in the beginning of our interview, she did not hesitate to share her trauma experiences to a male stranger, the interviewer. “Even though I was finding little difficulty with the new rules and regulations imposed by the Central Drukpa government, I never participated in any political activities neither did my husband”, she added. All of a sudden in 1992, the three soldiers came to her house and asked for her husband. Since he was not there at the moment, they thought he must have gone for the political activity against the state. “They then started to beat me and later each of them raped me turn by turn in front of my daughters until I was unconscious” she told with tearful eyes. She was very ashamed especially because it all happened in front of her adult daughters. The soldiers had threatened to kill her if she dared to report the case to the authority. “The local authority instead issued a warning to leave the country as soon as possible”, she added. Finally a few days after the incident, they left for Nepal. In the cultural Hindu context, rape implies irreversible spiritual pollution to the survivor and her family. It was thus a catastrophe for her to have been raped as a female Hindu. She said, “I used to wash my private parts several times a day in a hope to be clean but it was not only external cleanliness as my soul was destroyed from inside. Since then my husband started to hate and beat me. I was blamed for all this mishaps”.

Since then she started experiencing several symptoms such as chest pain, lower abdominal pain, headache, loss of appetite, dizziness, sleeplessness, flash backs, vaginal discharge and itching, and pain at and around the genitalia. “I became so frightened to see any soldier as it reminded me of the event”, she continued, “I sometimes felt that my life has now no more worth so I should commit suicide”. Suicide is also a taboo topic in the context, because suicide negatively affects reincarnation. She did not see any doctors and she felt she could not talk about the rape to anyone because of the stigma. She was finally brought to CVICT

clinic and treated by psychologist and psychiatrist who diagnosed PTSD. She gradually got rid of some of her symptoms. But even at the time of the interview, approximately 10 years after the rape, she was feeling weak and was unable to do any work. She said that she mostly stays at home.

Comments
The case underscores the importance of the context. Mrs. M. appears to be especially affected by the social consequences of the traumatic event of rape, which have great taboo in both Bhutanese and Nepalese context. There were several women raped during the army raid and their post trauma situation is more likely to be similar with that of Mrs. M. The case shows that a mere PTSD diagnosis only tells a small part of the story.

Case 2
Mrs. S is 43 years old mother of seven children who got married at an early age of 11. "All of a sudden, a few weeks after marriage, I started to speak and do irrelevant things", she said. She experienced deep fear and was not willing to stay at home. After one year's of staying with her husband, she went back to her parent's home and stayed there for 6 years. Even though several traditional healers treated her with rituals and sacrifices of animals, because they thought that the illness was due to bad spell or spirits of evil, she did not improve. She used to suffer more during full moon or no moon days ("*ausi purne lageko"*). "People called me by the name of a mad woman (*bahula aimai*) and I was embarrassed", she explained. She was unable to do any household things so her parents had to look after her.

She further said, "I later moved to my husband's home again and had been living there. In 1991 Drukpa soldiers came to our house and started to beat my husband. They took him and imprisoned for 3 years under severe torture. They did not do anything to me because I looked quite sick. However,

they asked me to leave the country with my children as soon as possible". She felt unsafe in Bhutan and thus followed her neighbors' path to Nepal as a refugee leaving all her land, cattle and house behind in Bhutan. She is currently living with her youngest son in the camp.

Immediately after her arrival, she visited the doctor in the camp and she received psychotropic medication and extensive counseling. She gradually started to feel better though she did not get rid of her symptoms completely. "I am afraid that I can never manage to be alive without pills, she further added sadly "I am almost abandoned by my husband and four sons who are in India. I wish to be with them but they still feel that I am a mad wife and mother." She was wondering why her family has such feelings. Even her own brothers, who live next to her in the same refugee camp, do not like to visit her, according to her narrative. She usually stays at home and goes to literary classes. Although she feels quite weak, she is taking care of herself and her child. Since she does not have any work in the camp, she stays mostly at home.

Comments

This case shows that the experience of refugee trauma must be seen in the context of other important aspects of the person's life, such as pre-trauma experiences and pre-trauma illness, and societal attitudes towards mental illness. It further illustrates how family and relatives deal with a mentally ill person. Moreover, early marriage especially for girls is a quite common practice in this population. We can also hypothesize that her early childhood marriage and premature sexual intercourse may have predisposed her to the psychopathology.

Case 3

Mrs. K, a 44 years old and married woman, is currently living in the Bhutanese refugee camp. She is literate and farming was her family's major occupation in Bhutan. Their income was quite sufficient to support the whole family. "After 1990's popular mass demonstration in southern Bhutan, the Royal army and Bhutanese authority started to arrest and torture the southern Bhutanese of Nepalese origin. The situation was full of terror and uncertainty. Soldiers came to our home and arrested both my husband and me in 1994 and imprisoned us in a school that has been temporarily converted into a detention center", she elaborated on what happened to her in Bhutan. In fact, almost all the schools were closed

for such purposes. Both of them were beaten severely during detention. She was finally released on the fourth day after she had agreed to leave Bhutan soon. She further added, "The authority gave me very little money for our house and property and forced me to sign on a paper where they had written that I was willingly leaving my country." She first went to India and then came to Nepal with her children in the year 1994. She felt very sad after she became a refugee. The sadness became worse when whatever wealth she had brought from Bhutan was robbed from the camp.

After seven months of imprisonment and severe torture, her husband was released and he then came to the refugee camp. Eventually he died in 1997 and she felt more lonely and helpless. She had several physical symptoms when she came here as a refugee. She complained of backache, headache, burning sensation over all the body, sleeplessness, fearfulness and nightmares. She felt more hurt whenever she thought about Bhutan and the torture that she received during her detention. She was initially treated at the health center but later was referred to the CVICT clinic. There she was seen by a doctor who started prescribing her Amitryptiline. She felt better and was on the same medication for almost 5 years. She has been off the medication for last 6 months, but she has started to re-experience the similar symptoms. She is afraid if she has to take pills forever to get rid of her symptoms. She said, "Despite the symptoms, I was able to perform most of my daily activities. But I could feel the difference in strength before and after having this illness". She also told that every one in her family and neighborhood was co-operative to her.

Comments

This narrative illustrates how the whole family was tortured and imprisoned in Bhutan and its consequences in terms of mental illness. It also shows the several other traumatic events in addition to the physical torture. Yet, Mrs. K's symptoms did not interference with her daily activities. This could possibly be explained in two ways. One possibility is that she could have coped well with the situation and her illness, thus she was functioning quite well. Other possibility is that all mental illnesses are not severe enough to lead to disability.

Case 4

Mr. G, a 33 years old, married man, came to Nepal as a refugee in 1992. He was born with clubfeet. His parents consulted traditional healers in Bhutan but it did not help. He never went to doctor for its treatment because he believed that there was no cure for such an illness. "I think my disability may be due to bad karma, i.e., bad and unfaithful activities in my past life", he said. Moreover, his parents were ignorant about his treatment. "Among seven children born to my parents, me and an elder brother of mine have clubfeet and others are absolutely normal. I have one daughter and one son. The son also had the same deformity but this was recently corrected by surgery" he explained. He can not walk long distance because it causes pain to his feet. He feels sad and unfortunate but nobody from his family and society hates him for his deformity. Instead, they love and show sympathy to him.

He had an interesting story to share about his marriage. He was little bit nervous to say, "I was attending a school in the camp and in the meantime fell in love with a beautiful woman. She was married but separated. She was living with her maternal uncle. We decided to marry and live for each other. We were sure and certain that her family would not allow her to marry with a disabled man like me. Thus, we both decided to run away from our families and to hide ourselves for several days." His elder brother was very much worried in the beginning to hear this news but later he did help them. In the beginning, her family had threatened to kill him for taking her away. Later, her uncle and others told that they would accept the marriage if they could once talk with them. He further explained, "One day, representatives from the camp authority and her uncle gathered at my brother's place. When her uncle saw my wife, he got so angry and started to beat her. He was so furious and was wondering why she could not find any other normal man in the camp". In this cultural context, it is usually hard for parents to let their daughters marry a disabled man. After lots of argument and quarreling, her family finally decided to let her marry with him. Now, his family is quite happy despite his son having similar problem as mentioned earlier. While going for his son's treatment, he had also inquired for his possibility of surgery. But he was told that it was too late by then. Otherwise, he does not have any problem and he is loved by all his relatives, family member and neighbors.

Comments

This narrative of Mr. G illustrates the deeply rooted stigma associated with disability in Bhutanese refugee community. This became more obvious while seeking to establish

marital relationship between disabled man (Mr. G) and a normal woman. This case has also illustrated the beliefs of Mr. G's parents, who believed that there was no cure for his disability, so they did not seek for any help. It also shows how a person with such a handicap can live a constructive life integrated in the community with good interpersonal relationships, and that the physical handicap does not necessarily represent a social handicap in the long term.

5.0 DISCUSSION

5.1 QUANTITATIVE STUDY

5.1.1 Torture and assessed disability

Both the tortured and non-tortured groups were found to have similar patterns of disability in the four different assessed domains of disability: personal care, family, household and social activities. Even though we were measuring disability with respect to these four domains, we observed that an individual who had scored a certain degree of disability for a domain was likely to score almost the same degree of disability for all other domains too. This indicates that assessed disability is not specifically for a particular role of an individual, but it affects several roles simultaneously. Among the disabled refugees, three fourths in both the groups were found to have minimal disability in each domain. This indicates that most of the disability detected in this study may not be clinically very

important. Only one in the tortured group who was found to be grossly disabled for personal care was a known case of PTSD for a long time and had also scored positive for four out of six assessed CIDI disorders signifying the importance of PTSD diagnosis and comorbidity in terms of associated disability.

We found that the rates of disability in any of the four domains for tortured and non-tortured group were similar. We also showed in our univariate analysis that almost all the assessed psychiatric disorders were equally associated with disability in both the groups despite much more higher prevalence of the disorders in the tortured group. This may be because CVICT had been providing psychiatric and counseling services to the tortured group for several years. Thus, they had better access to the health care services than the controls of non-tortured. We argue that torture survivors with psychiatric disorders were well treated and rehabilitated so that we did not find significant difference in disability between two groups in spite of higher psychopathology among the torture survivors.

As was the case with torture status, torture related variables such as time since torture and time since displacement did not appear to have any association with disability among tortured refugees. This finding of no association between torture status and disability, and high prevalence of disability among Bhutanese refugees as well is quite consistent with the previous findings among Bosnian refugees (Mollica et al, 1999). Thus, although torture as a refugee trauma has received considerable attention in very many studies (Basoglu, 1994, 1997; Mollica et al, 1998,1993), we found torture not to have an association with disability compared to other refugees on a group level. This finding also supports other researchers' views (Basoglu, 1993; Shrestha et al, 1998), that refugees do suffer from variety of other problems apart from the physical torture, which were not all assessed and controlled for in our study.

5.1.2 Comorbidity and disability

Psychiatric comorbidity and associated disability has got enough attention from previous researchers (Kessler, 1999; Olfson et al, 1997; Druss et al, 2000). We showed that comorbidity of PTSD with either persistent pain or specific phobia or dissociative disorders

possesses greater likelihood of disability. Comorbidity between PTSD and depression, and PTSD and GAD did not appear as risk factors for these tortured Bhutanese even though they had been shown to bear significant association with disability in other studies (Mollica et al, 1999; Kessler et al, 1999). The finding that more the number of diagnosed psychiatric disorders, the more the Odd's of disability both for tortured and non-tortured groups signifies the importance of comorbidity and its consequences in terms of disability.

5.1.3 Predictors of disability

Predictors of disability among tortured refugees were present physical health status, PTSD and specific phobias after controlling for all other socio-demographic and illness variables. The association between PTSD and disability had been shown among Vietnam veterans (Zatzick et al, 1997) but such an association was not seen among refugees in the Balkans (Mollica et al, 1999). The association of present health status with disability is consistent with similar study among Bosnian refugees where perceived poor health status was reported to predict disability (Mollica et al, 1999). Earlier researchers (Stein & Kein, 2000; Olfson et al, 1997) have found association of disability with social phobia, however, its association with specific phobia in refugee population has not been reported.

On the other hand, except for present health status, we had different set of predictors of disability for non-tortured refugees. The association between present health status and disability was even stronger in this group, which may be because the non-tortured cases had more untreated present health problems. The other predictors identified were generalized anxiety disorder and older age group (>55 years). This would probably explain the high prevalence of disability in this group despite lower prevalence of PTSD. This finding of association of generalized anxiety disorder with disability in the non-tortured group is quite consistent with the findings of National Comorbidity (Kessler et al, 1999) and other surveys (Olfson et al, 1997, Mendlowicz & Stein, 2000). The association between old age and disability is quite an expected finding.

We showed that both the groups had almost equal disability status irrespective of the torture status, and that the predictors of disability were different between the groups. The variance of disability among torture survivors could be explainable by its association with

highly prevalent PTSD and specific phobia disorder. Since several authors (Basoglu et al, 1994; Shrestha, 1997) have reported the significant association between torture and PTSD, one could disagree for not having direct association of torture status with disability in our data despite having association between PTSD and disability status. However, as discussed earlier, tortured refugees had better access to health services and had received psychiatric services for several years. That is why they were found to have almost equal disability as non-tortured refugees. Furthermore, those torture survivors might have been exposed to several other not assessed traumatic stresses other than torture. On the other hand, association of disability with GAD and older age group could explain the high disability among non-tortured refugees.

5.1.4 Strength and weakness of study

The torture survivors were identified on the basis of self-report, so torture status was not validated. We did our study several years after they became refugees and interviewers were not blinded regarding the torture status of our respondents. We had controls of non-tortured refugees matched for age and gender, yet the two groups might have differed in some other not assessed variables. We had less representation of females in our sample because we had fewer females registered as torture survivor.

Moreover, we used CIDI as one of the outcome measure, which has not been well validated either for this particular or any other non-western population. Similarly, disability was measured with the use of WHO DAS-S, which has not been used for such an epidemiological survey and has not been validated. Given the high rates of disorder (Van Ommeren et al. 2001) and the low rates of identified major disability, it is possible that the CIDI, as adapted in Nepal, overestimated disorders and that the WHO DAS-S, as assessed

by the doctors, underestimated major or severe disability. Furthermore, our study was a cross-sectional study so that the strength of our prediction is limited. Because of several limitations in refugee set up for validation of instruments, we did not seek for inter-rater reliability for disability measurement and CIDI diagnosis.

Yet, our study was in a large population based sample in a developing country with comparison groups. The psychiatric disorders were assessed with well-established structural interviews with cultural modification of its probe flow chart discussed else where in details (Van Ommeren et al, 2000). Even though CIDI assesses disability and impairment due to each disorder and symptom, we had to assess the global disability and we chose WHO DAS-S as recommended by earlier researchers (Janca et al, 1998; Kessler, 1999). Apart from disability assessment with WHO DAS-S, we also had brief medical examination of all the respondents by doctors. In this way, none of the participants with physical disability were included in our study.

5.2 QUALITATIVE STUDY

5.2.1 Understanding of mental illness

We observed that there is no single terminology in this cultural setting that could represent all ranges of mental illness as understood in the biomedical model. Thus, *mansik rog* or *mana ko rog* (literal translation of mental illness) to most of the participants directly meant an illness of madness with bizarre, abnormal behaviors, distinctly different from that of a normal individual. For many, "*mana*" the site of defect responsible for *manko rog* was located at soul, either inside or near to the heart. The others said that mental illness is due to something wrong at their brain or head, which illustrates people's own way of understanding human anatomy and pathology as discussed by Helman (2000). Kaplan (1999) has found similar understanding of mental illness in his study of a community in Nepal. Furthermore, our FGD has also elicited that people suffering from mental illness may present with nonspecific pain all over the body, which is consistent with the high

persistent pain disorder detected in this community (Van Ommeren, 2001). This warrants further research.

5.2.2 Causes of mental illness

A variety of causes for mental illness were elicited. On contrary to the western world, where people attribute their mental symptoms to the causes within individual or in the natural world, these refugees attributed mental illness mostly to supernatural causes and little to social and natural causes. This is because most of the refugees are Hindus who have quite unique way of seeing life as a never-ending cycle, and a single human life they believe, is just a minor part of it. They usually explain life and complex events using the supernatural world, and thus mental illness could not be apart from it. Among the several supernatural causes, *junagali lageko* (spirit met in jungle) was quite interesting. Moreover, refugee trauma and their passive life without any active work in the camp was suggested to be the contributing factors for their mental illness, the latter requires consideration for their effective rehabilitation. The point that mental illness is related to position of planets and *karma* is note worthy and future researchers should explore more on the topic through examining explanatory models in detail.

5.2.3 Family members and help seeking practices

As stated by Kleinman (1988), the appreciation of meaning is bound within a relation, it belongs to the sick person's spouse, a friend, or caregiver or to the patient himself. Our discussion with the family members showed that they share the similar beliefs, values and practices as their mentally ill members do. Help seeking practices were quite consistent with other studies in third world countries (Kleinman, 1988; Kaplan, 1999; Saeed et al, 2000), because the refugees would first like to consult traditional faith healers. Very similar to what was observed in China (Kleinman, 1988), all the family members agreed that mental illness not only affects patients, but also badly affects their families. This is of great importance in our parts of the world where family is the best social support system for ill and handicapped people. Furthermore, their belief system that all mentally ill people, irrespective of their type of illness, get the same sleeping tablets is interesting and at the same time is note worthy for planning mental health services. Because most of the refugees

thought that mental illness is not a curable disorder, there is a need of effective health services consisting of psychiatric clinics, counseling services and health education campaigns.

5.2.4 Disability

Disability on the other hand was mostly understood as visible physical disability mainly due to congenital causes as experienced by Hellander (1995). The literally translated Nepali word *apanga* for disability did not carry the full meanings of disability similar to previous findings (Talle, 1995) so *bimari bhayeko* and *sape* were identified during the FGD. Similar to the mental illness, Bhutanese refugees paid more emphasis on the supernatural causes for disability, which is not strange taking into account of Hindu culture, with strong beliefs of reincarnation, past life and *karma*. Yet, some biomedical causes such as drugs and lack of nutrition in pregnancy were added. As one of the aims of this part of study was to explore the consequences of mental illness especially in terms of disability, most of them admitted that mental illness could cause disturbances in one's daily activities and responsibilities. This indirectly supports the findings of our survey, which has detected disability related to mental illness among the same population. Also, their saying that disability could lead to mental illness is note worthy.

5.2.5 Traditional healers

Especially in the context of inadequate understanding of the healing process as argued by Kleinman (1988), FGD with traditional healers helped us to understand how they manage mental illness and disability. As expected, we found that they had more supernatural theories both for mental illness and disability, and they claimed themselves as better healers to deal with those cases. Their attitude towards modern health system was not totally negative because many of them said that they would like to refer those cases to health facilities, if they think that the causes are not supernatural or if they do not know how to deal with. Thus, any mental health program should make best use of these existing easily available resources in the community. Furthermore, it was noticed that more traditional healers have emerged in the camp in the last few years, which may be a positive way of coping, because it has proved to be a good way of earning and raising one's status

in the society and traditional healers are often able to provide social support to people with problem.

5.2.6 Stigma attached to mental illness and disability

Stigma associated with disability and mental illness among Bhutanese refugees as revealed by FGD and narratives is quite consistent with other studies (Kaplan, 1999; Whyte, 1991; WHO, 2000). But still, because of the supernatural and religious beliefs for its causation and considering them as gift of God, family and society usually takes care and helps mentally ills and disabled people, even though the latter are not considered as heroes in this society as observed in Nicaragua (Bruun, 1995). Regarding the stigma associated in establishing marital relation, we found that there are more problems, especially for mentally ill or disabled women, different from what was observed in Uganda (Sentumbee, 1995). This is because in this male dominated society, even a disabled or mentally ill man is sometimes considered superior to a normal woman. Rehabilitation program should pay more attention to the women in this community.

5.2.7 General comment about FGD

In this cultural context, we felt that it is not easy to convince the participants that they are the resource persons. We tried our best to facilitate the discussion and rather not to influence their idea. We still experienced that it was more like a group interview rather than a group discussion. Interaction of an individual with the moderator was more than with the group members. One possible reason could be that most of the participants were either barely literate through informal education or were illiterate, and they had no prior experience of group discussion. Other possibility could be the subject matter itself because mental illness is not an easy subject that people would like to talk about. We thus agree with Strickland (1999) that cultural traditions and individual variation such as education, age, traditional orientation influence focus group discussion. Moreover, some other weaknesses of our FGD should be of note. The participants were familiar with each other

because they were from the same camp. Therefore, in this context where people usually have close social relation with each other, it is not easy to have focus group discussion among the participants who did not know each other before. Female groups seemed more informative and this is important information for future research. This might have happened because we had separate FGD for females except for a group of traditional healers, which was mixed up of 2 male and 2 female traditional healers. As argued by Stevens (1996), separate focus group discussion for females will facilitate discussion, especially in those societies where females are given lower status than their male counterparts. Furthermore, we also experienced 'talking in circle' and 'story telling' during focus group discussion as experienced by Strickland (1999), which unnecessarily prolonged the duration of discussion. Despite these limitations, we felt that FGD is an informative research tool for qualitative study.

5.3 CONCLUSION

Our quantitative study revealed high psychopatholgy and associated disability. Even though we detected high prevalence of psychiatric disorders and disability among Bhutanese refugees, it does not necessarily demand for urgent treatment services to all of them because many were diagnosed with mild illness and minor disabilities. Those who were found to have minor disability (15%) would just need some sort of social supports and those who were found to have obvious or more severe disability (5%) would need better curative and rehabilitative services. Since the respondents did not seem to be aware of counseling or psychotherapy, it should be a part and process of any intervention.

Yet, this study detected association of disability with specific phobia indicating the need to explore this in future studies. This study further confirmed the association of old age,

present health status, PTSD, and GAD with disability. Our findings may have a clinical implication that PTSD, specific phobia and GAD should be treated appropriately in time, because as discussed earlier, they are more likely to lead to impairment of several functions. However, further studies are needed among refugees living in third world countries to generalize our findings. Thus, future researchers should consider including instruments that measure disability to further explore the association between disorders and disability.

Our qualitative study focussed more on perception of mental illness and disability. All the FGD revealed that the Bhutanese refugees have their own ways of understanding mental illness and disability. Their explanation was deeply influenced by their religion, culture, and belief system. This finding is in concordance with the finding of non-refugee population living in the third world countries (Kaplan, 1999; Patel et al, 1995; Sheikh & Furnham, 2000). The values, norms and belief systems are in fact deeply rooted with the culture people grow up. Based upon it, they have their own explanation for illnesses including mental illness (Helman, 2000), which should be explored to make any mental health program effective in the population (Kaplan, 1999; Kleinman, 1988). Furthermore, this part of study also supported the findings of quantitative study that mental illness could lead to disturbances in one's several functions.

Although both the quantitative and qualitative approaches have their limitations and strengths, an integration of both the methods is useful in psychiatric research. Qualitative research methods thus provide a useful methodological complement to standardized interviews in adding meaning and context to psychiatric research (Patel, 2000). We especially encourage other researchers to incorporate both qualitative and quantitative approaches in epidemiological studies outside the west where local belief systems vary from that of the researcher.

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INFORMED COSENT FORM

Introduction to interview

Interviewer / facilitator and recorder gives his name and tells why he / she is here.

Purpose of study

I would like to know what had happened to you in Bhutan that eventually made you to be a refugee. I am also interested to know more about the nature of your illnesses and its consequences in terms of disability. In addition, I would like to know your knowledge, attitude and beliefs on mental illness and disability. Finally, I am interested in details of illnesses and its outcome in some of your cases.

What is your benefit?

If you have any health problem, doctor will check you and provide necessary treatment. You will be brought and taken back to the camp by us and will be provided light snacks. Your sincere help makes us understand your problem in better way so that concerned authority can tackle it accordingly.

What do we expect from you?

We kindly request you to be honest and tell freely what you are asked. We encourage you to give your feelings and opinions. If you feel uncomfortable or our question hurts you, you can simply refuse to reply and you are even free to quit the rest of the interview or discussion.

Confidentiality

Before we start, I will assure you that this is confidential and will not be used by any authority against you. If you do not want to participate now, you are free to refuse it.

Do you agree to participate? **YES** **NO**

Note: People with severe mental illness and disability will not be included in this study.

GUIDELINE QUESTIONS FOR FOCUS GROUP DISCUSSION

A. For Mentally ill and Disabled refugees

- What do you understand by mental illness and what are its causes?
- What could be the consequences of mental illness?
- What do you understand by disability? What could be the causes for it?
- How do you feel to be mentally ill / disabled?

- Where did /do you go to get treatment for your illnesses?
- Do you see any relationship between mental illness and disability? What kind of?
- How do your neighbors and friends deal with you?
- How does your illness affect in establishing marital relation with you or your family members?

B. <u>For Family members of mentally ill / disable refugees</u>

- What do you understand by mental illness and what are its causes?
- What could be the consequences of mental illness?
- What do you understand by disability? What could be the causes for it?
- How do you feel to be with mentally ill / disabled people?
- Where did /do you take your family member to get treatment for their illnesses?
- Do you see any relationship between mental illness and disability? What kind of?
- How do your neighbors and friends deal with your mentally ill / disabled member?
- How do their illness affect in establishing marital relation with you or your family members?

C. <u>For Traditional healers</u>

- What do you understand by mental illness and what are its causes?
- What could be the consequences of mental illness?
- What do you understand by disability? What could be the causes for it?
- How do you feel to treat mentally ill / disabled?
- How do you treat mental illness and disability?
- Do you see any relationship between mental illness and disability? What kind of?

GUIDELINE QUESTIONS FOR CASE STUDIES / NARRATIVES

Case studies will be prepared with the following guidelines.

- Briefing about his or her past back ground in Bhutan
- Inquiry of his / her illness with focus for mental illness
- Inquiry of the treatment both with traditional healers and modern medicine
- Any associated disability with the illness
- Feeling and experiences after being mentally ill / disabled
- Current health and social activity status

WHO DAS-S QUESTIONNAIRES

NOTE : THE FOLLOWING QUESTIONS REFER TO R'S **CURRENT** (WITHIN 1 MONTH) LEVEL OF FUNCTIONING; PLEASE DO DETAILED INTEROGATION WITH RESPONDENTS AND USE YOUR CLINICAL EXPERIENCE TO DRAW UP AN ESTIMATE FOR THE FOLLOWING QUESTIONS:

DR8 PLEASE RATE THE R'S LEVEL OF FUNCTIONING RELATED TO PERSONAL CARE (I.E., PERSONAL HYGIENE, DRESSING, FEEDING)

0= NO DISABILITY (FULLY ABLE)
1= MINIMAL
2= OBVIOUS
3= SEVERE

4= VERY SEVERE
5= GROSS DISABILITY (CAN ONLY FUNCTION WITH ASSISTANCE)

DR9 PLEASE RATE THE R'S LEVEL OF FUNCTIONING RELATED TO OCCUPATIONAL/DAILY WORK (I.E., PAID ACTIVITIES, STUDYING, COOKING)

0= NO DISABILITY (FULLY ABLE)
1= MINIMAL
2= OBVIOUS
3= SEVERE
4= VERY SEVERE
5= GROSS DISABILITY (CAN ONLY FUNCTION WITH ASSISTANCE)

DR10 PLEASE RATE THE R'S LEVEL OF FUNCTIONING RELATED TO LIFE AT HOME (I.E., INTERACTING WITH FAMILY MEMBERS, PARTICIPATING IN HOUSEHOLD ACTIVITIES)

0= NO DISABILITY (FULLY ABLE)
1= MINIMAL
2= OBVIOUS
3= SEVERE
4= VERY SEVERE
5= GROSS DISABILITY (CAN ONLY FUNCTION WITH ASSISTANCE)

DR11 PLEASE RATE THE R'S LEVEL OF FUNCTIONING RELATED TO LIVING IN A COMMUNITY (I.E., PARTICIPATING IN LEISURE, SOCIAL AND COMMUNITY ACTIVITIES)

0= NO DISABILITY (FULLY ABLE)
1= MINIMAL
2= OBVIOUS
3= SEVERE
4= VERY SEVERE
5= GROSS DISABILITY (CAN ONLY FUNCTION WITH ASSISTANCE)

DR12 ESTIMATE TOTAL DURATION OF DISABILITY

0 = NOT APPLICABLE (R DOES NOT APPEAR DISABLED)
1 = DISABILITY HAS LASTED SO FAR LESS THAN ONE YEAR
2 = DISABILITY HAS LASTED SO FAR ONE YEAR OR LONGER
3 = IT IS UNCLEAR HOW LONG THE DISABILITY HAS LASTED

DR13 MENTION R'S SPECIFIC ABILITIES THAT MAY BE IMPORTANT IN THE MANAGEMENT OF CARE FOR R'S FUNCTIONING IN THE FAMILY OR COMMUNITY (E.G., GOOD LOOKS, OUTSTANDING PHYSICAL STRENGTH, ABILITY TO WORK AS A HEALER)

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MAP OF NEPAL AND BHUTAN

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